SURVIVALISING AMONG HOMELESS PEOPLE WITH TUBERCULOSIS: A GROUNDED THEORY STUDY

A Thesis submitted for the degree of
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By

Magdalena Whoolery

Faculty of Society and Health
Buckinghamshire New University
Brunel University

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ABSTRACT

Tuberculosis (TB) continues to be one of the world's most devastating and deadly diseases. Its reach is not confined to developing countries, but is manifest in pockets of high infection in cities like London, and among vulnerable groups such as the homeless. To date, the majority of research on TB in London has been quantitative, and little has drawn on the experiences of homeless people living with the disease.

A qualitative Grounded Theory study was undertaken to provide insight into the experience of being homeless with TB in London. The Grounded Theory approach was utilised to systematically collect and analyse data from 16 in-depth interviews of homeless people with TB at three Central London TB/chest clinics.

The result is the emergence of the theory of *Survivalising*, which reveals a basic social process experienced by homeless people with TB, with four distinct social patterns: Zoning-out, Bottoming-out, Self-realisation and Healing.

Zoning-out relates to the daily quest to survive the harsh realities of social exclusion. Personal health is neglected, overshadowed by the desire for inner escape.

Bottoming-out represents a personal crisis point where individuals are no longer able to view themselves, or the world, in the same way - creating a catalyst for positive change.

Self-realisation sees a new conceptual order accepted, fundamental attitudes toward life and living transformed and interest in seeking health and social services increased.

Healing is about fixing a fractured existence, rebuilding relationships, restoring health and building a new and better life. Adherence to TB treatment becomes a high priority.

The results of this study contribute to the overall body of research knowledge on TB, and provide a theory to augment our understanding of the homeless-TB experience. Survivalising enables health professionals and policy makers to conceptualise and deliver appropriate TB care, according to the unique requirements of individuals.

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LIST OF ACRONYMS

BCUC	Buckinghamshire Chilterns University College
CDC	Centers for Disease Control and Prevention
CINAHL	Current Index to Nursing and Allied Health Literature
DDU	Drug Dependency Unit
GT	Grounded Theory
HIV	Human Immune Virus
LFU	Lost to Follow-up
MDR-TB	Multi-drug resistance - Tuberculosis
MREC	Multi Research Ethics Committee
MXU	Mobile X-ray Unit
NHS	National Health Service
NOID	Notifications of Infectious Disease
ODPM	Office of the Deputy Prime Minister
PHLS	Public Health Laboratory Service
RCT	Randomized Control Trial
TB	Tuberculosis
TST	Tuberculin Skin Test
UK	United Kingdom
UNICEF	United Nations Children's Fund
USA	United States of America
WHO	World Health Organization
XDR-TB	Extensive Drug Resistant Tuberculosis

PART I

The Universal Declaration of Human Rights Article *25:*

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control

(United Nations 1948)

CHAPTER ONE – THESIS OVERVIEW

1.1 Introduction

This introductory chapter provides a foundation for subsequent chapters. It begins by revealing the background for the study[1] and provides a brief discussion of the phenomenon of interest. This leads to the purpose of the research, including the aims and objectives of the study. Finally, a summary of the chapters within the thesis is presented.

1.2 Background

Two billion people, equal to one-third of the World's population, are infected with Tuberculosis (TB) (World Health Organization 2007a). Although TB is curable, 5000 people each day die, resulting in nearly two million deaths each year (World Health Organization 2007). TB is fundamentally a disease of poverty affecting the most vulnerable. While the majority of TB cases are in the developing world, a number of London boroughs now have TB rates comparable with some developing countries and TB rates in London continue to increase (Department of Health 2004), posing a serious public health risk to all.

Throughout the world, homeless people suffer more illness and die sooner than the more privileged (World Health Organization 2005). Poor physical health is closely linked with homelessness and the correlation between poverty and illness is evident in the literature (Bottomley 2001, Pleace *et al* 1999, Rosenheck *et al* 1998, Grenier 1996, Townsend *et al* 1992). Available studies suggest that homeless people have complex social and psychological problems and are especially vulnerable to TB (Story *et al* 2004, Ormerod 2000, Rayner 2000, Jackson 1996, Barnes 1996). Homeless people experience problems in accessing health care and are less likely to adhere to TB treatment. Yet the majority of TB research has focused on general treatment interventions, mainly epidemiological studies, through a quantitative

[1] See Appendix A, which presents the researcher's growing awareness of the significance of her personal experiences of homelessness to the research topic.

research lens. Little is known about the meaning of TB to homeless people, and how they cope with it in their lives. Therefore, much is unknown about the experiences of homeless people with TB, resulting in a serious research gap. The researcher became acutely aware of the need for a qualitative study capable of gaining this information.

1.3 Purpose

The aim of this research was to understand the experience of living with TB and being homeless. The research focused on the following objectives:

- To develop a substantive theory on the homeless experience of tuberculosis.
- To gain insight and knowledge of the experience of being homeless and diagnosed with TB.
- To understand how homeless people deal with issues of TB and homelessness.
- To identify factors that impact homeless people taking their TB treatment.

The researcher posed the following research question:

> What does having tuberculosis mean to homeless people and how does this impact their opportunities to complete treatment?

To answer the broad research question and fulfil the research objectives mentioned above, Grounded Theory was used as a systematic methodology within a qualitative design. Grounded Theory was appropriate because there were no existing theories on the research topic and it provided a new perspective in a research area dominated by quantitative medical studies of TB treatment (Stern 1994).

1.4 Structure of the Thesis

The thesis is divided into three parts. Part I includes the literature review in Chapter Two, which incorporates an overview of homelessness and tuberculosis. The chapter examines the issue of homelessness illustrates the health and social problems

encountered by homeless people, revealing the TB connection and the problems in adhering to treatment and accessing health care. This section covers TB from a bio-medical and social science perspective and provides a brief discussion of the problem of TB in London.

Part II of the thesis is organised into two chapters. It begins with Chapter Three, which identifies the research methodology, ascertains key philosophical and methodological debates, and presents the framework underpinning the study. Chapter Four sets out and outlines the study design, including ethical considerations and an examination of the data collection and the analysis methods used in the study.

Part III of the thesis is composed of three chapters. Chapter Five presents the results of the current study; it outlines the study findings and reveals the theory of Survivalising, its categories and their properties. Chapter Six provides a discussion of the results in relation to the available literature and explores the strengths and limitations of the current study. Finally, Chapter Seven takes into account the recommendations arising from the current study.

1.5 Conclusion

The researcher discovered that much of the current literature regarding the topic of TB was quantitative and did not encompass the experiences of homeless people. As a result, a serious research gap was identified. The researcher, therefore, recognised the need to conduct a qualitative study that could elicit this information. The complex experience of being homeless with TB is the phenomenon of interest, thus the purpose of the study, its aims and objectives reflect the need to understand and discover the meaning of the phenomena from homeless people themselves.

CHAPTER TWO - HOMELESSNESS & TUBERCULOSIS LITERATURE REVIEW

2.1 Introduction

This chapter provides an overview of the subject of homelessness and tuberculosis. It begins by considering the nature of homelessness, its social distribution and the factors that lead to it. It then proceeds to discuss health and social problems, comprising of tuberculosis (TB), its pathology, clinical presentation, diagnosis and treatment. The chapter offers a consideration of the history and epidemiology of TB and a brief discussion of the TB problem in London. This is followed by an exploration of homelessness and TB, the issues of access to health care, adherence to treatment and concludes that more qualitative research is needed in this field.

2.2 The Nature of Homelessness

There is no universally agreed definition of homelessness, as definitions currently in use are, to a degree, founded on ideological notions about the circumstances of individuals (DCLG 2008b, Chahal 1999, Crisis 2006). Due to the lack of consensus, there are various definitions of homelessness, and vigorous debate regarding which is most appropriate (Office of the Deputy Prime Minister (ODPM) 2004, Pleace *et al* 1999). Current definitions are constructed from the typology of homelessness and the homeless experience, which can incorporate legal definitions and are influenced by (as well as influence) the data available on different homeless groups (Chahal 1999). Broader definitions, with more inclusive criteria tend to be adopted by non-governmental organisations, while Government agencies often use criteria that are more restrictive. These different definitions and criteria result in inconsistent, and at times contradictory, information and data on homelessness. Broader definitions tend to increase homelessness figures, while criteria that are more restrictive lead to lower estimates. The result of using different definitions affects how homelessness is presented, perceived and understood.

The UK Government defines homelessness in two ways: statutory and non-statutory. Those classified as statutory homeless include households that qualify for re-housing by local authorities. This comprises homeless households with children and those defined as vulnerable under the terms of the Homelessness Act 2002. Homeless people that do not qualify under the homelessness legislation are referred to as non-statutory homeless. They are primarily single, and commonly referred to as rough sleepers, and do not qualify for public housing (DCLG 2008b, DCLG 2007a, DCLG 2006a, Pleace *et al* 1999).

However, the definition of homelessness implemented for this thesis is both inclusive of statutory and non-statutory individuals with the following classification:

> The homeless are people who are either literally roofless or who are forced to live in insecure, overcrowded, dangerous, illegal or temporary accommodation such as bed & breakfast hostels (B&B), women's refuges, hostels, on friends/relatives floors and squats (Lewis *et al* 2003, McMurray-Avila *et al* 1998) (see Section 4.4.2.1).

It is important to note that this definition of homelessness is more than just "rooflessness" but also extends to different groups, under various situations, such as women who are in insecure or in temporary accommodation (for example, hostels, bed and breakfast, refuges). The significance of this definition is that it distinguishes and highlights the diverse nature of homelessness, encompassing various categorisations of the homeless condition, and is therefore representative of the homeless population.

2.3 The Extent of the Problem

The UK Government has set up the Homelessness and Housing Support Directorate within the Department of Communities and Local Government (DCLG), with the mandate to manage the homeless problem in England, requiring local authorities to develop appropriate homeless strategies (DCLG 2008b, DCLG 2007a, DCLG

2006a). On 5 May 2006, the responsibilities of the Office of the Deputy Prime Minister (ODPM) were transferred to the DCLG (DCLG 2007a).

The ODPM (2004) states that each year 200,000 households experience homelessness, or the risk of homelessness. Crisis, a UK homeless charity, reports a higher annual figure of 400,000 single homeless people in Great Britain. These include those staying in hostels, B&Bs, squats, on friends' floors and in overcrowded accommodation (Kenway & Palmer 2003). More recently, in 2005, 162,990 households (not individuals) were found to be homeless by local authorities (Crisis 2006). Regardless of the different figures used, homelessness continues to be a major problem in British society.

DCLG statistics for the first quarter of 2007 state that 37,300 decisions were made relating to housing applications considered by local authorities, 20% lower than the same period in 2006. However, it is estimated that 87,120 households at the end of the quarter were in temporary accommodation (DCLG 2007b). While the figures are accurate within set definitions, government statistics may not reflect the true level of homelessness, as they merely record those who apply for support from their local authority, i.e. the statutory homeless, and do not document whether these people manage to locate permanent accommodation (Lemos & Goodby 1999).

These statistics only captured the number of households who came forward, were found to be homeless through no fault of their own and who were in priority needs groups. These priority groups are households with dependent children, including pregnant women, and those with a mental or physical health problem (DCLG 2007a, Lemos & Goodby 1999, Pleace *et al* 1999).

The Government has maintained that their statistics on homelessness are reliable (ODPM 2004). While this may be true, according to the definition of homelessness they propose, it is important to note that these figures do not encompass hidden and hard to reach homeless groups - namely single homeless people. Government figures are therefore under-estimating the current homeless problem, and more importantly

are systematically excluding at risk groups not accepted as statutorily homeless (Lemos & Goodby 1999). These exclusions have important implications for the provision of a broad range of social services and support for the homeless.

The Government has attempted to establish the extent of this problem by asking a number of local authorities to conduct a pilot study of single homeless people using services (ODPM 2002[2]). From a sample of 1,400 single homeless people, the study found that: 77 percent were male; 29 percent were aged 18-25; 38 percent were aged 25-39 years old; 84 percent were of white British ethnic origin and six percent were Black. When questioned where they had slept the night before: 41 percent stated hostels; 21 percent with family or friends; 14 percent sleeping rough; nine percent in their own accommodation and three percent had stayed in squats. In this sample 29 percent had been in prison; 15 percent in local authority care and five percent were previously in the army (ODPM 2002). These results provide some insight into the demography of the non-statutory homeless, but it is important to note that the survey findings are not representative of single homeless people throughout the UK.

The age, sex and racial composition of homeless people has changed dramatically. For instance, in the past rough sleepers tended to be single, white and middle-aged men (Pleace *et al* 1999). This group has come to include young people, women (Dibblin 1991), ethnic minority groups (Chahal 1999) and recent entrants, including people seeking asylum (ODPM 2002). Individuals from black or minority ethnic backgrounds are almost three times more likely than white people to be statutorily homeless (ODPM 2002, Harrison 1996) and more than three times as likely to be homeless and living in hostels (Harrison 1996).

In 2002, London had the highest number of homeless people in the country, with around 24 percent of the national rate (ODPM 2002). In 2003, Shelter, a homeless charity, announced that homelessness in London was at its highest recorded level ever (Shelter 2003). According to their survey, over 50,000 households were in

[2] This is the most recent study commissioned by the Government on the specific issue of rough sleepers to assist policy development for primary health care.

temporary housing, with over 7,000 of these in bed and breakfast hotels and an additional 14,000 single homeless people were living in hostels (Shelter 2003).

2.4 Causes of Homelessness

There are many reasons that people become homeless. These are often classified under two groups of factors, often referred to as structural and personal (ODPM 2002, Rosenheck *et al* 1998).

Structural factors relate to the general supply of affordable housing. In the UK, the demand for affordable housing has drastically risen, putting strain on the housing and rental sectors. Subsequently, this has led to increased rental costs and an increased number of people applying for social housing. Between 1979 and 2001, 1.7 million UK council homes have been sold under the Right-to-Buy scheme. This initiative led to the transfer of social housing to private ownership, reducing the capacity of local authorities to re-house homeless families (ODPM 2002).

Of late, the international housing market has experienced momentous problems as a result of instability in global financial markets. In the UK, individuals are struggling with housing issues and in particular finding it a difficult to obtain a mortgage. As a result, house prices have fallen dramatically (DCLG 2008a).

According to the UK Government, the number of repossessions remains far below what they were in the 1990s. However, in response to these uncertain times, the Government has published their most recent document (DCLG 2008a), which sets out immediate steps to help deal with the current housing problems and asserts in it the required actions to prevent homelessness. Although the measures aim to provide independent information and support on financial issues, such as debt advice and strengthening the National Homelessness Advice Service, their main focus appears to be with families who face financial difficulties (DCLG 2008a). In line with their strict definition of homeless people, and those at risk of homelessness, it is questionable whether these new Government initiatives will have any impact on vulnerable groups, such as the single homeless.

While structural factors are well documented and understood, less is known about the personal, social and economic factors that cause homelessness. People who have moved in and out of institutions have been found to be at risk of homelessness, in particular, young people who have been in care, patients leaving hospital and mental health units and those who have been released from prison (ODPM 2002).

The most recent Government document on health and homelessness, produced in March 2004 by the ODPM, acknowledges that homelessness is a major problem that is increasing in British communities. The document claims that the cause is rooted in a:

> …complex interaction of structural problems, including the supply and accessibility of housing and personal problems, such as debt, relationship breakdown and poor health (ODPM 2004:4).

Although these are significant causes of homelessness, the document appears to overlook other possible factors. A report, produced by Lemos & Goodby (1999) for Crisis, documented sixteen major causes of homelessness, including time in local authority care, school exclusion, contact with the criminal justice system and previous service in the armed forces. These complex and varied causes of homelessness are reflected in the health and social problems that the homeless experience.

2.5 Complex Health and Social Problems Among the Homeless

The homeless are a diverse group, and often reflect the local population. Consequently, homeless people experience different forms of adversity due to societal structures and personal vulnerabilities and therefore have unique needs. Homeless people often have multiple health problems and experience a combination of issues, such as mental ill health, substance abuse or involvement in risky practices, such as commercial sex work (Croft-White & Parry-Crooke 2004).

Homelessness is a complex phenomenon and has been described as both an effect and a cause of serious mental and physical health problems (Rosenheck *et al* 1998). This claim is corroborated by Pleace *et al's* (1999:30) study, which found that people sleeping rough frequently reported:

> …feelings of stress, anxiety and depression which were associated either with homelessness itself or with events preceding homelessness. The physical hardship, poor diet and danger of being on the streets all had a stressful effect, but it was perhaps the isolation of homelessness and the attitude of society towards them that they found most difficult.

The isolation, sense of rejection and depression experienced by homeless people could lead to drug or/and alcohol dependency. Studies have indicated that homelessness leads to intense alienation and the loss of essential social skills (Pleace *et al* 1999, Fisher & Collins 1993).

Everyday stressful experiences, vulnerability to the elements, poor nutrition and a lack of basic requirements can lead to deterioration in a homeless person's already poor health status (Rosenheck *et al* 1998, Townsend *et al* 1992). Homeless people often have multiple health and psychological problems. It is common for a rough sleeper to have a respiratory condition, a drug and alcohol dependency and suffer from depression (Rayner 2000, Pleace *et al* 1999, Rosenheck *et al* 1998).

In one study, drug and alcohol dependence was found to make the diagnosis of mental health problems difficult for health professionals because it was unclear whether the homeless person's behaviour was a result of the dependency or a mental health problem (Pleace 1998). However, the evidence appears to show that, when compared to the general public, homeless people have high levels of poor mental and physical health (Story *et al* 2004, Rayner 2000, Pleace *et al* 1999, Rosenheck *et al* 1998), are more likely to engage in substance abuse, and have repeated contact with the criminal justice system (Story *et al* 2007, Hahn *et al* 2006, Story *et al* 2004). Some of the common health problems exhibited by homeless people will be explored in the following section.

2.5.1 Substance Misuse & Mental Health Problems

People sleeping rough are more likely than the general population to have an alcohol or drug dependency (Hahn *et al* 2006, Pleace *et al* 1999). A study by Croft-White & Parry-Crooke (2004), underscores the vulnerability of single homeless people, who have complex and multiple health needs. Croft-White & Parry-Crooke (2004:7) state that:

> multiple health needs are pervasive in the lives of single individuals who are homeless. Persistent health problems include severe psychiatric conditions, ongoing substance abuse issues, and learning disabilities. These often co-occur along with an array of physical health difficulties that are frequently under-diagnosed and untreated.

In highlighting the issue of substance use, Griffiths (2002) purports that about 70 percent of homeless people misuse drugs and half are dependent on alcohol. Supporting this claim are the results of a national study of homelessness, in which Anderson *et al* (1993) discovered that a high proportion of single homeless people reported heavy drinking or alcohol related health problems; this applied to a third of people sleeping rough and one in ten people in hostels and B&Bs (Anderson *et al* 1993). In concurring, Bines (1994) study also reported alcohol use as a coping mechanism used by homeless people to deal with difficulties in their lives:

> … You've got to have something to keep you going…whether that's drinking or taking drugs, you've got to have something…it's an anaesthetic half of it, just to take your mind off the situation you are in…Or to knock you out at night (Bines 1994:16).

> Well it blocks out all the bad memories and blocks out all the pain you are getting at the moment…and you drink and that because then you forget (Bines 1994:16).

In a study by Gill *et al* (1996), people sleeping rough were found to be dependent on opiates (heroin & derivatives): 37 percent were using drugs and 18 percent were

dependent on opiates (Gill *et al* 1996). In another study, those using a night shelter were self-reported as dependent on drugs (Pleace 1998). Compared to the general population homeless people are eight times more likely to attend an emergency department because of drug overdose (North *et al* 1996).

Poor mental health among homeless people is a serious problem, with between 30 and 50 percent suffering from mental illness (Griffiths 2002). This often makes them less able to deal with their health issues and engage with service providers. The incidence of mental health problems, defined by Bines (1994:11) as "depression, anxiety and nerves", were excessively high among single homeless people; those sleeping rough were eleven times more likely than the general population to report psychological problems. The study found mental health problems in 28 percent of individuals in hostels and B&B's, 36 percent of day centre users and 40 percent of soup run users. This is compared to only five percent of the general population. Rough sleepers were most likely to have mental health problems and more likely to have been inpatients at a psychiatric hospital.

In the Bines (1994:7) study many of the homeless participants described their feelings of depression:

> There's a terrible feeling of being lost, belonging to nobody and feeling that nobody cares.

> I got so depressed in this (place) that I slit my wrists open and I had to have stitches (hostel resident).

Elderly homeless people are particularly vulnerable to suffering mental health problems. Those who have been long-term patients on mental health units are at greatest risk, as they might not have the necessary skills to deal with the social world outside of the mental health system. A study from the United States found that individuals had been made homeless, not so much by the fact that they were discharged from psychiatric units, but because of the way in which they were

discharged (Lamb & Talbot 1986). The study discovered two significant factors: firstly how well the individuals were prepared for discharge; and secondly what arrangements were in place for the individual's ongoing support. These two aspects affected whether individuals would be made homeless (Lamb & Talbot 1986).

These findings are further corroborated by research in the UK that led to the adoption of discharge policies for individuals with mental health problems. In particular it pointed to the risk of becoming homeless and recommended that health professionals engage with the necessary social support networks to support these individuals' discharge (Access to Health & Medical Campaign Project 1992, Kelling *et al* 1991).

Subsequently, the Department of Health stated that all hospitals are required to have formal admission and discharge policies, ensuring that homeless people are identified on admission and when discharged, the primary care and homeless services are informed (Department of Health 2003).

More recently the DCLG (2006b) has issued joint guidelines with the Department of Health on hospital admissions and discharge for homeless people. The main aim of this new protocol is to ensure that no individual is discharged from hospital to the streets or to unsuitable accommodation.

2.5.2 Physical Illness

A comparison of health status between the general population and the homeless reveals that homeless individuals suffer a high burden of poor health (Lewis *et al* 2003, Rayner 2000, Martens 2001). Poor physical health is intimately linked with homelessness and the connection between poverty and illness is clearly described in the literature (Lewis *et al* 2003, Bottomley 2001, Pleace *et al* 1999, Rosenheck *et al* 1998, Grenier 1996, Townsend *et al* 1992). The average life expectancy (1991-92) of rough sleepers was 42 years compared to the national average of 74 for men and 79 for women (Grenier 1996). The enormity of this statistic can be highlighted by comparison to that of a developing country. For instance, in South Africa life

expectancy in 2000 was 47 years due to the impact of Aids (Kalipeni *et al* 2005), a higher life expectancy than homeless people in the UK.

Research by Bines (1994) compared data on the self-reported health of single homeless people and the general population in the UK. This comparison showed that there was a significantly higher incidence of physical health problems among single homeless people, compared to the general population. Notably recurring chest or breathing problems and frequent headaches were twice as common among people in hostels and B&B residents and three times as common among those sleeping rough. Wounds, ulcers and other skin conditions were twice as frequent among day centre users and three times as frequent among soup run users. Musculoskeletal problems were twice as likely among people sleeping rough compared to the general population, and three times as many people sleeping rough experienced visual problems (Bines 1994).

In the Bines (1994) study single homeless people declared more health problems than the general population, but those sleeping rough reported the most health problems of all. Four out of every ten people in hostels and B&B's, and six out of every ten sleeping rough had more than one health problem compared with just two out of ten people in the general population. Generally, the homeless felt that homelessness had affected their health:

> It certainly affects your health…your body gets completely run down…you're not eating properly, you're not sleeping properly and you're not getting proper heat (Bines 1994:7).

> If you're homeless on the street, you can pick up all sorts of diseases, you get scabies, all sorts, skin diseases that's the common one (Bines 1994:7).

These findings support those of Anderson *et al* (1993) that the general health problems that affect rough sleepers are cardiovascular, musculoskeletal and dermatological. All these conditions are made worse, or more difficult to treat, by sleeping rough.

The Bines (1994) study is a significant piece of research for several reasons. First, it is based on a national survey of a representative sample of single homeless people. Previous studies have focused on specific geographical locations (Anderson *et al* 1993, Critron *et al* 1995, Alexander 2000, Corbett 1998), but Fitzpatrick (2006) and Greve (1991) claim that while a serious issue in London, homelessness is a national problem. By providing a national view of the homeless problem, Bines's (1994) study addresses a key gap in research and offers new insight through a comprehensive look at homelessness and health in the UK.

Second, the research combined qualitative and quantitative approaches; a collective method recognised to enhance rigour (Robson 2002, Parahoo 1997).

Third, the Bines (1994) study was the largest to be carried out since the late 1970s (Drake 1981), with a homeless sample of 1853 individuals. The second source of data came from an annual survey of a nationally representative sample of 10,000 individuals (Bines 1994). The large sample size and national focus provide a valuable source of information about single homeless people and their health and is an effective means to address threats to validity by avoiding error due to random variation or chance. Finally, the scope of the study has positive implications for generalisability.

Nonetheless, there are two major limitations. The first is that it was conducted in 1991, sixteen years ago. The concern here is that the research may be out-dated, particularly when you consider that the demographic composition of the homeless has changed, and continues to change considerably (Pleace *et al* 1999). In the past, the homeless population was primarily composed of males and the elderly. Today it encompasses more women and ethnic minorities (ODPM 2002, Chahal 1999, Rosenheck *et al* 1998) (see Section 2.3).

The second limitation of the research is the suitability of Bines's (1994) comparison group (general population). Studies of the health of homeless individuals should use

suitable comparison groups. It is evident that it is insufficient to compare prevalence rates between homeless people and the general population (Victor 1997). According to Victor (1997), this is because differences between the homeless and the general population are so great, and that certain issues may be masked when a seriously disadvantaged population is compared to the population as a whole. Consequently, comparisons of health status should come from other low socio-economic populations (Victor 1997).

A serious physical condition among some homeless people is HIV. Research shows that the rate of HIV infection among the homeless is high (Weiser *et al* 2006, Toro *et al* 1998, Big Issue 1998, Kipke *et al* 1995). Because of poverty, men and women may sell sex for money due to drug addiction or they may simply be forced to by others (Drake *et al* 2005). Commercial sex workers are at risk of a range of sexually transmitted diseases including HIV. Intravenous drug use also increases a homeless person's risk of developing HIV and hepatitis. A study by the Big Issue[3] Foundation (1998) found that 13 percent of homeless people were sharing needles; seven percent had hepatitis C and five percent were HIV positive. HIV weakens the immune system, thereby increasing susceptibility to TB. Consequently, homeless people whose immune systems are compromised by HIV are more likely to develop TB (Jackson 1996, Colson *et al* 1994). Furthermore, TB is a leading cause of death among people who are positive (World Health Organization 2007).

Pertaining to this concern are the important findings of Story *et al* (2007[4]) Pan-London study (see Appendix B) which discovered that the overall rate of diagnosed HIV was 9.6 percent among a sample size of 1994 TB patients, but rates varied considerably by TB centre (see Section 2.14 for a more in depth look at Story *et al's* 2007 study).

[3] The 'Big Issue' is a street newspaper published on behalf of and sold by homeless people.
[4] Story A, Murad S, Verheyen M, Roberts W, Hayward A C (2007) Tuberculosis in London - the importance of homelessness, problem drug use and prison. Thorax. 62: 667-67. Note that the researcher now uses her married name Whoolery. Verheyen, as referenced here, is her maiden name.

It is important to note that one of the NHS targets to control TB in London by April 2002 is that all patients with TB should be recommended and offered the HIV test (London Assembly Health Committee 2003). However Story *et al* (2007) recent survey found that many patients had never been offered a HIV test and HIV status was unknown in 61 percent of cases, while 23.8 percent of those tested were found to be HIV positive. As mentioned earlier, because the rate of HIV infection among the homeless is high, this finding has considerable implications for effective TB control in London.

Available studies and literature reveal that homeless people face immense health related problems, which span from minor issues such as skin conditions to more serious and life threatening ones like HIV (Lewis *et al* 2003). Some of these health issues directly influence on TB (i.e., a compromised immune system due to poor living conditions, inadequate diet, or HIV increase the risk of acquiring TB).

2.6 The Nature of Tuberculosis

Tuberculosis is an infectious bacterial disease caused by the bacterium Mycobacterium tuberculosis, also known as 'the tubercle bacillus' (M.tuberculosis or M.Tb), (CDC 2008, Higgins 2006). It commonly affects the lungs, but can reach any part of the body (CDC 2008). Tuberculosis is the general name for a whole group of diseases associated with the presence of tubercule bacillus, of which there are two manifestations: pulmonary and extra pulmonary (Sreeramareddy *et al* 2008).

Pulmonary tuberculosis is the most common, and the most serious, as it can be transmitted to others (MacPherson 2005, Health Protection Agency 2005a). Extra-pulmonary tuberculosis exists when infection is present outside the lungs. In this case it can affect any part of the body including, the kidneys, bones or lymph nodes (Sreeramareddy *et al* 2008, MacPherson 2005). However, the two forms of TB can co-exist and typical progression is from the lungs (pulmonary) to locations outside the lungs (extra-pulmonary) (Sreeramareddy *et al* 2008).

TB can be either latent or active. With latent (or inactive) TB, the individual is infected by the tubercle bacillus but the disease is dormant. There is no active disease process and it is not transmissible to others. In contrast, active TB the disease progresses and is capable of transmission to others (CDC 2008).

2.7 Transmission of Tuberculosis

TB is usually spread by the inhalation of infectious salivary droplets containing the tubercle bacillus, which are coughed or sneezed by an infected person (World Health Organization 2007, MacPherson 2005). This aerosol is inhaled into the nasal passages and lungs of a susceptible person in close proximity (Higgins 2006, Maher *et al* 1997). However, not all forms of TB are infectious. Those with TB in organs, other than the lungs, are seldom infectious to others, nor are people with latent TB (World Health Organization 2007).

Individuals with pulmonary TB that is infectious, especially those with bacteria that can be seen on microscopic examination of the sputum, are characterised as 'smear positive' (see Section 2.9) (Higgins 2006). Prolonged close contact with a person with TB, for example, living in the same household, is usually necessary for infection to be passed on. The risk of becoming infected depends principally on the length and intensity of the exposure to TB. It can also take many years before someone infected with TB develops the full disease (infectious).

2.8 Pathology and Natural History

As explained above, TB is transmitted by droplet infection. Consequently, this transmission is more likely to occur when individuals live in overcrowded and unhealthy conditions (Higgins 2006, Maher *et al* 1997).

Once inhaled, over a period of several weeks, the tubercle bacilli travel to the alveoli[5] in the lungs, where they are engulfed by macrophage cells[6]. The bacilli

[5] Alveoli are tiny air sacs in the lungs in which exchange of oxygen and carbon dioxide takes place between air and the blood stream (Anderson 2002).

multiply inside the macrophage and then disseminate through the lymph vessels to nearby lymph nodes[7]. The immune system is then stimulated, observed with a simple diagnostic test called the tuberculin skin test (TST also known as Mantoux). In more than 80 percent of cases, the immune system destroys and removes the bacteria. However, in a small number of individuals, a defensive barrier is built round the infection. The bacteria are not killed, but rather lay dormant (Higgins 2006). This is called latent TB; the individual does not feel ill and, at this point, is not infectious (CDC 2008). Latent TB can be diagnosed by a TST (CDC 2008). Occasionally at the time of the initial infection, bacteria can get into the blood stream and can be carried to other regions of the body, before the defensive barrier is built (Higgins 2006).

In cases where the immune system fails to build the defensive barrier, or the barrier fails later, latent TB can become active. Active TB can spread within the lungs (pulmonary tuberculosis), to the lymph glands within the chest (intrathoracic respiratory tuberculosis) or develop in other part(s) of the body to which it has spread (extra-pulmonary) (CDC 2008, Higgins 2006, Beers & Berkow 2005).

In nine out of ten patients who harbour the tubercle bacillus who do not have symptoms or physical indication of active disease, their x-rays remain negative. These groups of individuals are not infectious. However, they do form a group of infected patients who may suffer morbidity in the future and then transmit TB to others. It is estimated that over 90 percent of cases of active TB come from this group of individuals (Beers & Berkow 2005).

2.9 Presentation and Diagnosis of Tuberculosis

Pulmonary TB affects the lungs and its early symptoms are often confused with those of other diseases. Initially, an infected person may feel generally unwell or develop a cough, which can be blamed on smoking or a cold. Later, they develop greenish or

[6] Macrophages are a type of white blood cells, or leukocyte and are essential to clear the lungs of dust and bacteria. They are found throughout the body, but especially in the lungs, where they specialise in the removal of bacteria and other micro-organisms.
[7] Lymph nodes are small masses of lymphatic tissue in the body that occur at various points along the major lymphatic vessels.

yellow sputum projected by coughing, which after a while may contain traces of blood. Individuals with pulmonary TB do not develop extreme pyrexia[8], although they frequently experience low-grade pyrexia and endure night sweats. The individual with this form of TB loses interest in food and consequently loses weight (Beers & Berkow 2005).

Chest pain is occasionally experienced due to air escaping in the pleural cavity between the lung and the chest wall (pneumothorax[9]). Sometimes shortness of breath can be due to fluid collecting in the plural cavity, which is called pleural effusion. The tubercle bacilli may disperse from the lungs to lymph nodes in the sides and back of the neck. Infection in these regions can penetrate the skin and excrete pus (Beers & Berkow 2005).

A medical examination for TB includes a medical history, a physical examination, a chest X-ray, and microbiological smears and cultures. Diagnosis of TB is also made by a positive tuberculin skin test, TST as mentioned earlier. The TST is intended to discover individuals who have been exposed to, and have the TB bacterium, but are not yet sick. TB can be confirmed by X-rays of the chest and microscopic examination of sputum. While patients with negative sputum smears are less infectious than those with positive smears, evidence suggests that they can still spread TB to others (Dutt & Stead 1994, Hernández-Garduño *et al* 2004). A positive smear signifies a substantial bacterial population in the lung lesions whereas negative smears can indicate a lower bacterial load. Thus, smear-negative cases do not require the same intensity and duration of treatment as smear-positive cases (Dutt & Stead 1994, Hernández-Garduño *et al* 2004). TB can also be confirmed by laboratory culture of the bacterium, which also indicates drug sensitivity and resistance.

2.10 Treatment of Tuberculosis

TB is curable if individuals adhere to treatment for the correct period, but can otherwise be fatal. Normally TB treatment lasts for six months. Individuals may be

[8] Pyrexia: Elevated body temperature (Anderson 2002).
[9] Pneumothorax: the presence of air in the pleural cavity between the lung and the chest wall.

prescribed isoniazid and rifampicin together for six months, with pyrazinamide added for the first two months (Health Protection Agency 2005b). In some cases, drug-resistance occurs, making the condition more difficult and expensive to treat, and treatment takes longer (Health Protection Agency 2005b). With first-line drug resistance the tubercle bacillus become resistant to the medicines of first choice. In the UK, these first line drugs are isoniazid, rifampicin, ethambutol and pyrazinamide. Although streptomycin is classified as a first line drug, it is rarely used and is not included in routine drug sensitivity testing.

In some cases mono-resistance occurs, where the individual becomes resistant to one of the first line drugs (Health Protection Agency 2005c). In other cases, multi-drug resistance (MDR-TB) occurs, and this is defined as resistance to both isoniazid and rifampicin, with or without resistance to other drugs, which can be fatal (Health Protection Agency 2005a, Health Protection Agency 2005c).

In England, around six percent of tubercle bacilli from individuals with TB are resistant to one or more anti-TB drugs and more than one percent show multi-drug resistance. If a person with infectious TB is left untreated, they will infect between 10-15 people, on average, every year (Department of Health 2004). Hospitalisation is seldom required since most patients are no longer infectious after two weeks of combination drug therapy (Higgins 2006, National Institute of Health & Clinical Excellence 2006).

World Health Organization (2007) has articulated anxiety over the emergence of an even more dangerous drug-resistant strain of TB than MDR-TB. Extensive Drug Resistant TB (XDR-TB) is MDR-TB that is also resistant to three or more of the six classes of second-line drugs (Todd 2007). The term XDR-TB was first used in 2006, following a survey by World Health Organization and the US Centers for Disease Control and Prevention (CDC). This virulent new strain leaves individuals almost untreatable with the existing anti-TB drugs (Todd 2007). The World Health Organization (2007) claim that XDR-TB has come about due to poorly managed TB

care. The problem has included erroneous drug prescribing practices and non-adherence to treatment (World Health Organization 2007).

2.11 The History of Tuberculosis

Poor housing conditions have always posed a serious hazard to public health. TB provides a classical and modern example of the close intertwining between health and housing (Bhatt *et al* 1995). The impressive fall in TB cases over the last hundred and fifty years is credited primarily to improvements in physical and social conditions, and the easing of poverty in our society (Story *et al* 2004). These social developments continue to influence the epidemiology of TB, nowhere in the UK more so than in London, where rates of TB have doubled in the last decade (Anderson *et al* 2007, Department of Health 2004). Today, TB appears to be centred in sub-groups of the urban population who experience poor/no housing, unemployment, and poor access to health and social services. Those most affected are the homeless who experience ineffective TB prevention, control and treatment (Interdepartmental Working Group on Tuberculosis 1996, Story *et al* 2004).

During the second half of the 19th century, before the arrival of effective TB drugs, treatment was for the most part based on a new movement for the treatment of TB, a movement called the sanatoria (Davis 1999). The sanatoria provided supportive care and isolation. They provided what was then considered the finest therapy at hand, a combination of good nutrition, fresh air, sunlight and rest (Davis 1999). It is debatable whether the sanatoria actually improved survival but the movement provided the benefit of isolating infectious people from the general public (Davis 1999). With the inception of effective drug treatments at the end of the 1950s, and later the chance of ambulatory treatment, the sanatoria began to close and for almost half a century TB rates fell in the UK (Davis 1999, Story *et al* 2004). This resulted in almost all TB treatment centres being closed and the remaining caseload was taken by the general chest clinics at outpatient departments (Story *et al* 2004). During this period, the capacity of the National Health Service (NHS) for long-term hospitalisation of TB cases all but disappeared. It is significant to note here that drug resistance to the first effective TB drug, streptomycin, was reported within one year

of its first use. This brought about the implementation of combination drug regimens as a standard therapy. At present, TB drug resistance is a global public health problem (Davis 1999, Story *et al* 2004).

Notwithstanding the existing and effective treatment, and an in defiance of the premature confidence of the medical profession, TB is making a major global comeback. The main problem to its successful control is the period of TB treatment required for a cure, as medication must be taken for a minimum of six months. The capacity to adhere to a long and difficult drug regime is the most important determinant of prognosis. It is well established that current TB treatment is extremely effective and can cure TB. However, drug treatment on its own is not enough to restore health and well-being, and should never conceal the other important factors such as good housing, mental health care, good nutrition and drug rehabilitation (Story *et al* 2004).

2.12 The Present Epidemiology of Tuberculosis

TB is a serious problem worldwide. It is responsible for more deaths than almost any other infectious disease, and was declared a "global emergency" by the World Health Organization in 1993 (Maher *et al* 1997). Today, TB continues to claim more than 2 million lives each year. These deaths occur among approximately 8 million new cases of TB that develop from a reservoir of an estimated 2 billion individuals infected with TB, which is equal to one-third of the entire world population. These dramatic statistics underscore the global threat posed by TB. The increasing number of TB cases worldwide is due to many factors, including the global pandemic of HIV/AIDS and the occurrence of drug-resistant TB, which in many settings has limited the effectiveness of current TB therapies (Maher *et al* 1997).

Cases of TB occurring in England, Wales and Northern Ireland are reported through Notifications of Infectious Disease (NOID) system and the Enhanced Tuberculosis Surveillance System. It continues to be a statutory requirement to notify all cases of clinically diagnosed TB. The aim of this notification system is for speed in detecting possible outbreaks and epidemics (Health Protection Agency 2005a). The Health

Protection Agency acts as the body that collates reports or notifications, enhances surveillance and provides detailed information on the epidemiology of TB.

Historically, trends in the epidemiology of TB have altered over time. In 1913, when the TB notification system was first implemented, it showed that recorded TB rates peaked in England and Wales in the early part of the twentieth century. During this period, 300 new cases per 100,000 people were reported every year. Since then, until the mid 1980s, the incidence of TB has been falling. In 1987, there were only 10 new cases per 100,000 people (Health Protection Agency 2005a).

In England, cases fell progressively until the mid-1980s but started to rise again in the early 1990s and TB has made a striking comeback in 2000. Tuberculosis rates in the UK remain higher now than at any other time since 1987. Levels of tuberculosis among the general population, however, remain low and the disease is primarily focused among certain high-risk populations (such as the homeless) (Health Protection Agency 2007).

In 2003, the Health Protection Agency reported that five percent of TB cases were accounted in children aged 0-14 years; 60 percent of cases in adults aged 15-44 years; 19 percent in adults aged 45-64 years; and 16 percent among adults aged 65 years and over. Thus, TB rates were highest in the 15-44 age group (18.2 per 100,000), and lowest in children aged 0-14 years (3.4 per 100,000) (Health Protection Agency 2005a). A close look at the current data in 2007 suggests that little has changed in the demography of TB (Health Protection Agency 2007). Results indicate once more that the 15-44 year age group accounted for the highest proportion of cases (62 percent); those aged 45-64 years accounted for 19 percent of cases; 14 percent were aged 65 years and over, three percent were aged 5-14 years, and the remaining two percent were aged below five years (Health Protection Agency 2007), Although not a dramatic difference, the findings show an increase in all the age groups.

Variations in incidence by ethnicity and place of birth are also notable. The risk of TB is known to be higher in people from minority ethnic groups, with sixty percent of TB cases born overseas (Health Protection Agency 2005a). People born overseas are 23 times more likely to develop TB when compared to people born in England and Wales (Health Protection Agency 2005a). The majority of cases in people born abroad occur after they have lived in the UK for several years (Health Protection Agency 2007, Higgins 2006).

In 2003, the Indian, Pakistani and Bangladeshi ethnic population made up the highest proportion of cases (36 percent), followed by the White (26 percent), and Black African (25 percent) populations. However, the highest TB rates appeared in the Black African ethnic population (283 per 100,000), followed by the Indian, Pakistani and Bangladeshi population (124 per 100,000) (Health Protection Agency 2005a).

Today there are currently over 8000 TB cases reported each year in the UK (Health Protection Agency 2007). The tuberculosis rate was 95 per 100,000 among the non-UK born population compared to four per 100,000 among the UK born. Like the 2003 data, the majority of individuals were from South Asia (47 percent) and Sub-Saharan Africa (37 percent) (Health Protection Agency 2007). Among cases born in the UK, the majority transpired in the white ethnic group (67 percent). Nonetheless, the highest rates were in the Indian, Pakistani and Bangladeshi (36 per 100,000) and black African (32 per 100,000) ethnic groups. The rate in the white ethnic group was three per 100,000 (Health Protection Agency 2007).

Like the 2003 results, among non-UK born population the largest percentage of cases were among Indian, Pakistani, Bangladeshi groups (45 percent), and the highest rate was among the black African ethnic group (395 per 100,000) (Health Protection Agency 2007).

The number of displaced people and refugees has increased as a result of international conflicts, thus the number of people applying for asylum has increased throughout the world. These conflicts in the developing world have forced refugees

to seek safety in countries such as the UK. Often refugees have come from counties where TB is endemic (Kessler *et al* 1997). Hogan *et al* (2005) note that TB in England and Wales has been associated with recently arrived immigrants. However, a TB screening pilot study carried out in Dover tested around 5,000 asylum seekers over a six-month period and found no cases of symptomatic TB. The explanation for the high rates of TB among minority ethnic groups (born outside UK/settled in UK) has been described as having dormant (latent) TB. This is a result of an infection caught months (or even years) earlier, which may develop into symptomatic TB due to poverty, old age or a compromised immune system (Bothamley *et al* 2002).

According to Story *et al* (2007), most TB patients, particularly foreign-born ones, were smear negative on diagnosis**,** demonstrate good adherence to treatment and have high rates of treatment completion (Story *et al* 2007). One third of UK born cases have social characteristics that affect their ability to access TB services and take treatment compared to 13 percent of the foreign-born TB patients. Around half (47.5 percent) of all foreign-born TB cases had been resident in the UK for five or more years prior to onset of disease (Story *et al* 2007).

This supports the findings of the Rose *et al* (2002) study that suggest that TB occurred among some ethnic minority groups after individuals had been in the UK after five years. Rose *et al* (2002) discovered that much of the TB occurring in the Black African ethnic group in London was in those who have been in the UK for at least 5 years. This suggests not so much the "importation" of TB, but the strong influence that underlying social issues such as poverty play in its manifestation. Nevertheless, the focus of much of the political and media interest has been on the high rates of disease among immigrant communities (Hogan *et al* 2005, Daily Mail 2002). This discourse has led to a great impetus in research looking at TB from an ethnicity perspective. It is important to take into account that surveillance data in England and Wales is limited to specific patient characteristics, such as age, gender and ethnicity. Therefore, explanations of the resurgence of TB have often emphasised issues of ethnicity and immigration, irrespective of patient's social characteristics, without sufficient discourse on its social context.

2.13 Tuberculosis in London

Every year around 350 people in England die from TB (Department of Health 2008). The exact mortality figure given by the Health Protection Agency (2008) in 2006, for England and Wales was 359. However, deaths occurring in 2006, but not registered until 2007 are not included in this figure (Health Protection Agency 2008).

The incidence of TB varies across different parts of the country, with most new cases occurring in major cities - particularly London (Health Protection Agency 2007). In 2001, London recorded 38 new cases per 100,000 population, compared to less than five in Southwest of England (Department of Health 2004). More recent surveillance data from 2006 show a further increase in new cases in London, which today accounts for the largest proportion of cases (40 percent) and the highest rate (44.8 per 100,000) (Health Protection Agency 2007). There are also substantial variations in incidence of TB within cities, with as much as a thirty fold difference between London Boroughs (Higgins 2006). As mentioned earlier, TB rates in London have doubled in the last 10 years and a number of London boroughs now have TB rates comparable with those in some developing countries (Anderson *et al* 2007, Department of Health 2004).

2.13.1 Comparison of Epidemiology of TB in New York City & London

Various authors have compared the TB crisis in London to that of New York City (Hayward & Coker 2000, Morris & McAllister 1992, Coker 1998, Department of Health 2004). This comparison is worthy of note, and is reflected in the Governments action plan against TB (Department of Health 2004), which recognises similarities between the cities. Hayward & Coker (2000) state that, if an epidemic similar to the one seen in New York City in the late 1980s and early 1990s is to be prevented, vital steps are necessary to reinforce TB control in London. Following this serious warning, the Chief Medical Officer acknowledged that a comparison of epidemiology of TB in New York City and London is important and lessons can be learnt from New York City's TB experience (Department of Health 2004).

New York City suffered an epidemic of TB between the late 1980's and early 1990's with multi-drug resistant patients in countless hospitals. Drug resistant TB was discovered in 21 percent of homeless people living in New York City (Morris & McAllister 1992). Substantial reinvestment in TB services by the US Government decreased cases by 59 percent, from a peak of over 3,700 during 1992 to less than 1,000 in 1998. In addition, the prevalence of multi-drug resistant TB fell by 91 percent (Hayward & Coker 2000). This shows that extensive reinvestment in TB services has a major impact in lowering TB rates and multi-drug resistant TB.

The United Kingdom experienced a rise in TB notifications during 1988, but they have since stabilised, with the notable exception of London, where the rise has been more pronounced and has not yet decreased. London contains over half of the notified annual cases of TB (Health Protection Agency 2007). Thus, while New York City has seen a remarkable drop in cases due to substantial investment in TB services, London appears to have suffered from under investment in TB services.

The rise in TB rates in London resembles that which was witnessed during the first ten years of the New York City epidemic (Hayward & Coker 2000). As in New York City, incidences of TB vary significantly in different parts of London, with the highest rates in areas of poverty and with large ethnic minority populations (Hayward & Coker, 2000, Brudney & Dobkin 1991, Hayward 1998). Central Harlem, an impoverished neighbourhood in New York City, suffered the highest TB rates with 79 cases per 100,000 in 1980, increasing to 170 per 100,000 in 1989 (Brudney & Dobkin 1991). In comparison, Newham, Tower Hamlets, and Brent sustained the highest TB rates with 77-79 per 100,000 of the population, with some boroughs experiencing an increase of two or three fold in 10 years (Hayward 1998).

The rise in reported TB cases in the two cities has been predominantly among 15-24 year olds. Additionally, the two cities experienced similarities in the data regarding ethnic origin, with the highest incidence of TB among 'non-white' populations (Hayward & Coker 2000).

The 1994 statistics from New York City suggest that 50 percent of cases were among the African American, non-Hispanic population, 26 percent among the Hispanic population and 12 percent among others of unknown ethnicity (New York Department of Health 1995). In 1993, data from London categorised 40 percent of cases among people originating from the Indian Subcontinent, 31 percent among whites, and 29 percent among 'non-white groups'. TB cases increased from 1988 to 1993 in 'other non-white' populations, while there was also an upsurge of TB cases among all groups born in the UK. Consequently, Hayward & Coker (2000) argue that the 'importation' of TB on its own is merely one element in the rise of cases in London.

The New York City situation arose due to a multitude of factors. Three aspects appear to have had a fundamental influence. First, there was complacency at a political and economic level, as funding for TB control programmes were dramatically cut by the Government (Hayward & Coker 2000). Second, the New York City's Bureau for TB Control experienced bureaucratic failures in communication. This gave rise to inadequate interactions between hospital departments and community outpatient services (Hayward & Coker 2000). Third, New York City suffered increased poverty and social exclusion. Deprived areas were severely affected by poor housing, unemployment, homelessness and HIV/AIDS. This provided the setting for poor adherence with TB treatment (Hayward & Coker 2000). This widespread breakdown in medication adherence is argued to be integral to the epidemic of drug resistance in New York City (Hayward & Coker 2000).

In addressing TB policy, the UK's Chief Medical Officer promotes the philosophy of rising to the challenge by adopting "a can do philosophy," encompassing a clear national level plan, and "a build up of infrastructure and resources at local, state and national level". A similar commitment to that seen in New York City is viewed as necessary to control TB in the UK (Department of Health 2004:5). Although TB is now highlighted as a priority in Local Delivery Plans across London, rates continue to increase and more is needed to address this growing problem (Terence 2005).

The UK Government's TB policy, mentioned above, encompasses lessons learnt from experiences in the USA and UK. While there are fundamental similarities in epidemiology, homeless numbers, poor adherence, high levels of loss to follow-up and transmission of MDR-TB in London and New York, there are limitations to Hayward & Coker's (2000) comparison of US and UK data sets. The fundamental differences between the US and UK health systems should also be accounted for when drawing comparisons. While the UK has a National Health Service, the application of a diverse set of public and private funding and service schemes in the US could confound the findings, as well as overstate the relevance of policies and practices enacted under these different systems. It is important therefore, to consider these limitations when drawing comparisons or conclusions.

2.14 Homelessness and Tuberculosis

The rise in TB cases in the UK has had a direct impact on the lowest socio-economic groups, these being the most vulnerable in our society. Although TB is not in itself discriminatory, it has been described as a disease of poverty (Bhatti *et al* 1995). For a long time deprivation has been associated with TB, and all available studies point to TB being a serious and particular problem among homeless people (Story *et al* 2007, Rayner 2000, Ormerod 2000, Capewell *et al* 1986, Citron *et al* 1995, Patel 1985), especially those who are rough sleepers or hostel users (Woodhead 2000, ODPM 2002, Harrison 1996).

The evidence suggests that presently homeless people are one of the most complex group of clients within the health care system (Story *et al* 2007, Rayner 2000). This observation is supported by the Interdepartmental Working Group on Tuberculosis (1996), which claims that, because they lack a permanent address and have inconsistent medical records, individuals with TB are unable to receive the most effective care either as inpatients or outpatients.

Because of the greater incidence of alcoholism, substance misuse and malnutrition, a homeless person's susceptibility to TB is increased (Barnes 1996). Barnes (1996) study reveals the interconnection between TB infection and the homeless, finding

that the rate of new TB infections in this group is higher than previously thought. It shows that 50-70 percent of TB cases among the homeless are new cases rather than reactivated old, dormant infection (Barnes 1996). As outlined earlier, a diverse range of physical problems has been linked to the living conditions and lifestyles of homeless people (Martens 2001, Power & Hunter, 2001). Some of the homeless participants in Bines' (1994) study felt that sleeping rough made them particularly vulnerable and susceptible to poor health:

> There's germs all over the place… you can catch diseases from sleeping on the streets and that. It's full of germs (Bines 1994:7).

Underlying factors such as HIV, a poor diet, over-crowding and generally poor health are thought to increase a homeless person's susceptibility to TB (Story *et al* 2004, Barnes 1996).

Communicable diseases are of specific concern to health professionals, as well as the UK Government, for two reasons: the possible risk of experiential spread amongst the homeless living in cramped shelters; and the risk posed to the general public (Wright 1990). In particular, TB has become an important health and social issue in London, due in part to the recent dramatic rise in incidence. Additionally, Power & Hunter (2001) conducted interviews with 100 homeless Big Issue newspaper vendors and professionals dealing with the homeless in London. The results reveal that various health concerns were identified, including TB.

As described earlier, the epidemiology of TB in England and Wales has altered and epidemiological data suggest that TB is becoming increasingly a disease of a number of minority sub-groups (Anderson *et al* 2007, PHLS 2002). A collaborative study between the Public Health Laboratory Service (PHLS), the British Thoracic Society and the Department of Health, identified that notification rates in England and Wales were excessively high in urban areas, particularly in London (PHLS 2002, Ormerod 2000).

The Pan-London TB study (Story *et al* 2007), was a major cohort[10] survey designed to capture the characteristics of TB patients in London. The researcher's involvement was that of project co-ordinator. It involved collecting profile data, including patients' housing and household, economic circumstances, residency status, drug and alcohol use, previous treatment, and HIV testing and status, routes and delays in presentation, DOT and treatment delivery then a follow-up to determine their progress and to measure the development of different outcomes (Story *et al* 2007). (see Appendix B). The research was extensive and examined the profile of all TB patients in London that were or should have been on treatment on 1st July 2003 with a follow up in July 2004 (Story *et al* 2007).

The cohort included 1995 patients from all thirty-three London TB treatment centres. Completed forms were received from 1941 of the 1995 cases identified. This cohort was estimated to include >95 percent of all current cases known to TB centres in London, and was reviewed twelve months later to generate new insight into how known risk factors complicated management and affected treatment outcomes. Fifty-four Patients found not to be suffering from TB were excluded (Story *et al* 2007).

This survey found that a high proportion of TB patients in London have multiple and complex health and social needs. The evidence from the Pan-London TB study suggests that there is a higher incidence of TB among homeless people than among other groups of people. Likewise studies by Moss *et al* (2000), Salomon *et al* (2000) and Chaves *et al* (1997) have shown high levels of transmission in these groups (Pablos-Mendez *et al* 1997). However, the survey provides new evidence that indicates that rates of TB in these groups are much higher than among recent migrants (Story *et al* 2007). In line with these findings, Citron *et al* (1995) found that TB was twenty five times more prevalent among rough sleepers than the general population.

Those with a history of homelessness often had drug and alcohol problems and were overrepresented in the prison population. Together, drug users, the homeless and

[10] A cohort is a pre-defined group of research participants subjected to follow-up (Li Wan Po 1998).

prisoners made up 17 percent (321/1941) of TB cases. This highlights the entwined and complex combination of problems. These findings support the point made by The National Institute of Health & Clinical Excellence (2006), which acknowledges that overcrowding and poor conditions of homeless people and prisoners exacerbate TB transmission.

Story *et al's* (2007) study is important in outlining TB patients' social characteristics, particularly homelessness, as powerful determinants of poor treatment outcome. This supports the findings of prior studies (Ormerod 2000). The profiling form (see Appendix C) was a valid tool for data collection and successfully measured what it intended. Reliability was maintained as the method of data collection was consistent and all TB cases utilized a standard profiling form. The quantitative approach taken in this study succeeded in providing important information and increased understanding of the profile of TB patients in London. However, the researcher was keenly aware that the information collected would not speak to the issues of homeless people, encapsulate their experiences or express what it means to them to have TB.

As reported above, prisoners, homeless people and problem drug users comprise only 17 percent of the all cases, but their contribution to poor control is much greater. High rates of diagnosed infectious TB in these groups, and most likely undetected infectious cases, make further outbreaks almost inevitable. The strong correlation between patients' social characteristics and poor adherence, loss to follow-up and drug resistance, emphasise the need to improve TB care among homeless people, problem drug users and prisoners in London (Story *et al* 2007). Thus by improving the strategies to control TB, great effort needs to be made in reaching out to those most at risk, such as the homeless, to ensure their treatment completion (Story *et al* 2007).

While TB is recognised as an important health problem among the homeless, awareness by the clinical and research communities of the personal meaning of the homeless-TB experience is lacking. This gap in understanding has fundamental

implications for caring for this marginalised group, those who care for them and the public in general.

2.15 Access to Health Care

The homeless deal with substantial barriers to obtaining medical treatment. In the famous Black Report, Townsend *et al* (1992:367) wrote:

> There is no doubt that homeless people face additional health problems which put them in great need of health services, but at the same time they face greater barriers in gaining access to health care than the settled population.

According to a study by Robertson & Cousineau (1986), half the homeless people interviewed stated that during the previous year they had not accessed the care they required. Even when it was accessed, they often had difficulties in complying with the prescribed treatment (Brickner *et al* 1985, Wright & Weber 1987).

Despite the high levels of poor health and very high rates of TB infection, single homeless people are 40 times more likely than the general population not to be registered with a general practitioner (GP) (Grenier 1996). Shiner (1995) discovered that homeless people were disinclined to approach GPs because they felt they would be stigmatised or looked down upon. A study by Pleace *et al* (1999) reported that there was a general pattern of poor access to GP services by homeless people across the country, including London. As a result of their inability to register with a GP homeless people often make use of emergency department at their local hospitals (Pleace *et al* 1999). This study also discovered that nearly a third of homeless projects (30 percent) reported that their clients made use of emergency departments rather than GP services (Pleace *et al* 1999).

According to Fisher & Collins (1993), the problem of access to services is fundamentally an issue of perception, by the public and by health professionals. These authors claim that barriers to access are perceived by health professionals as homeless people's problems or fault, heavily influenced by observations that conjure

up stereotypical features of the homeless (Fisher & Collins 1993). They are viewed as mobile and thus cannot keep appointments, as loud and disruptive to other patients, "too smelly, too dirty and often drink too much" Fisher & Collins (1993:32). In highlighting this perception they cite the following extract from a report published by the Department of Health:

> Pathology among the single homeless is perhaps more apparent as deviant behaviour than as a physical illness. Very heavy drinking is extremely common, as also is excessive gambling – in many cases these activities are quite clearly beyond the individual's control. One of the doctors consulted felt that almost all the homeless men he had seen had serious personality problems and some were overtly psychotic (Department of Health 1974 cited by Fisher & Collins 1993:32).

Little has changed regarding perceptions of homeless people since the above publication in 1974. More recent research suggests that homelessness is still associated with 'deviant' or challenging behaviour and that barriers to access are the result of anxieties that GPs, their receptionists and other health professionals have about homeless people (Pleace *et al* 1999). Studies reveal the concerns that both GPs and hospital doctors have that the homeless may be difficult people and their presence in the health setting may disturb other patients (Martin *et al* 1992, Connelly & Crown 1994 and Pleace & Quilgars 1996). A study by Martin *et al* (1992) reported that health professionals in an emergency department had negative perceptions towards homeless people. These views were that homeless people were in part to blame for their medical condition, for instance because of drug or alcohol misuse. The health professionals believed that the use of the emergency departments by the homeless was inappropriate and that they would be better served by GP's. However, it is inappropriate to criticise homeless people as unsuitable patients because there is significant evidence indicating that the general population also use emergency departments inappropriately (North *et al* 1996).

These assumptions are manifested as discrimination and their supporting ideologies suggest the deviant behaviour of those accessing health care (McMurray-Avila *et al*

1998). These perceptions distract from the political, social and structural issues that fundamentally affect access. Therefore, some analysts maintain that the problem with access to health care is chiefly a result of poor access to affordable housing (Power *et al* 1999, Arblaster & Hawtin 1993). Poor housing conditions have been associated with a wide range of physical and mental health problems (Krieger & Higgins 2002).

Although it is generally recognised that homelessness and poor health are related, there appear to be few studies showing the link between housing and health (Lewis *et al* 2003, Thomson *et al* 2001). This is in part due to the difficulty of demonstrating empirical proof that such a link exists (Bines 1994). However, a study by LoBue *et al* (1999) found that supervised housing supported the treatment of TB among the homeless. This study showed that having a house resulted in improved completion of treatment and substantial cost savings when compared to hospitalisation (LoBue *et al* 1999). Similarly, a systematic review of the health effects of improved housing (intervention) indicated that health gains were made after housing improved (Thomson *et al* 2001). However, the review only looked at 18 quantitative studies (international/national) using small sample populations and lacked control for confounding factors, which ultimately may limit their generalisability. As noted earlier, the lack of evidence and large-scale studies may be due to pragmatic difficulties in conducting such research. Nevertheless, it has been argued that addressing housing issues offers public health benefits (Krieger & Higgins 2002).

Inequalities in access mean that treatment is available to some individuals, but not to the homeless who are the most vulnerable (Croft-White & Parry-Crooke 2004, Lewis *et al* 2003). This has serious implications for the treatment of diseases such as TB, since these inequalities promote disease transmission and drug resistant strains.

The complex medical and social problems of homeless people affect both access to and completion of treatment (Grange & Zumla 1999, Rayner 2000, McMurray-Avila *et al* 1998). Poor adherence to treatment leads to poor TB control and has played a significant role in the re-emergence of drug-resistant TB (Thiam *et al* 2007). Although TB remains one of the world's leading causes of death, it is the lack of

access to treatment that has led to the exponential growth and the emergence of fatal strains of multi-drug resistant TB. A major obstacle to TB treatment among homeless people is the provision of health care and follow-up (Jackson 1996). Homeless people frequently do not complete their TB treatment (Jackson 1996). In London, where there is a large homeless community, reported outbreaks of drug resistant strains have surfaced becoming a serious public health concern (Story *et al* 2007, Story *et al* 2004).

2.16 Adherence to Anti-Tuberculosis Treatment

Poor adherence with treatment has been documented as far back as Hippocrates: of late the topic of adherence has received immense interest from academics and clinicians with countless publications over the last thirty years (Haynes *et al* 2002).

Non-adherence is a core obstacle to eliminating TB and has led to its ineffective management (Tedeschi 1997, Grange & Zumla 1999). Barnhoon & Adriaanse (1992:291) support this assertion by stating:

> …in general, non-adherence with medical treatment is a major problem in tuberculosis control.

Pablos-Mendez *et al's* (1997) study found that in general poor adherence could not be predicted according to gender, age or level of education. The study showed that there was a higher rate of poor adherence amongst homeless people, alcoholics, drug users and HIV infected people. Various other studies have also found that membership of these groups correlated significantly with poor adherence (Story *et al* 2007, Evans 1995, Weise *et al* 1994, Sumartojo 1993).

Medication adherence is a pivotal factor in improved health outcomes of TB patients. Abrupt cessation of treatment has been held responsible for jeopardising TB control, and ultimately having direct and serious implications for individuals, health professionals, public health and the government (Edward *et al* 1999, Pablos-Mendez *et al* 1997, Maher *et al* 1997). A significant proportion of homeless patients in the

UK stop treatment before reaching its conclusion (Story *et al* 2007, Rayner, 2000). A number of studies have documented the association between health deterioration, re-hospitalisation and the poor health outcome of non-adherent patients (Pablos-Mendez *et al* 1997). Furthermore, poor adherence with treatment has not only been shown to undermine health improvements, but may exacerbate the disease or even accelerate its progress toward drug resistant strains, and even MDR-TB (Chan & Iseman 2002, Barnhoon & Adriaanse 1992). Currently in the UK, one in fifty TB patients is infected with MDR-TB (James 2000).

Poor adherence to treatment, loss to follow up and high levels of drug resistant disease are serious contributory factors leading to unrestrained transmission. In agreement with the findings of Quilgars & Pleace (2003), Story *et al* (2007) found that adherence to TB treatment was one of the most problematic issues for homeless patients. Consequently, high levels of non-adherence, particularly among homeless people, have been shown to lead to relapse and the emergence of drug resistant disease (Story *et al* 2007).

A serious outbreak of more then 260 single and multi-drug resistant TB (MDR-TB) cases in north London provided the first reported evidence of problems among homeless people, problem drug users and those with a history of imprisonment to TB control (CDR 2006). These population groups experience poor access to health services and have problems in adhering to drug treatment (Story *et al* 2004). Yet, despite this knowledge, data on these groups are not frequently gathered and the effects of these factors have never been measured (Story *et al* 2007). While homelessness is a known risk factor for MDR-TB (Concato & Rom 1994, Loddenkemper *et al* 2002), there have been no previous studies looking at the high levels of MDR-TB and acquired drug resistance among homeless TB patients in London. Story *et al* (2007) quantitative study provides important new evidence that homelessness was associated with MDR-TB in London. Homeless people had acquired MDR-TB following inconsistent and prolonged TB treatment that resulted from poor adherence (Story *et al* 2007).

The study by Calder *et al* (2001) suggests that health professionals need to recognise non-adherence with medication therapy in TB cases and to check that patients understand the signs and symptoms. Although patients are often held responsible for poor adherence, Grange & Zumla (1999:316) places the emphasis of fault, not on the patient, but on the health professional. This assertion provides a new view of what is often termed 'deviant' behaviour. As discussed earlier, a concept highlighted is that homeless individuals may believe that health professionals are reluctant to treat them due to their poor hygiene or mental illness, or because they assume they have come for shelter rather than for a medical reason (McMurray-Avila *et al 1998*). This implies that an apparent lack of respect can jeopardise adherence and follow up care (McMurray-Avila *et al* 1998).

Thus, when dealing with the health needs of the homeless, effective and successful outcomes depend on more than accurate diagnosis and quality treatment. Often success hinges on positive relationships with health professionals and consequently the patient's ability to adhere to the recommended treatment. The researcher argues that health professionals dealing with this vulnerable group need to be aware of their behaviour and attitudes, show patients respect and be non-judgmental. Andersson *et al's* (2001) study, using both qualitative and quantitative methods, supports the notion that the attitude of the staff can affect medication adherence. Furthermore, a study from India investigating factors responsible for non-adherence discovered that satisfaction with health care providers contributed significantly to the continuation of TB treatment (Barnhoon & Adriaanse 1992). A supportive ethic among health professionals is also encouraged by the World Health Organization, who state that health professionals need to address the social, cultural and ethnic factors for the patient receiving TB treatment within the community (World Health Organization 2005, 1999).

Health professionals face numerous obstacles in supporting this ability and establishing continuity of care (Whitehead 2001). Even though there is a strong relationship between homelessness, TB and poor adherence (Story *et al* 2007, Pablos-Mendez *et al* 1997, Evans 1995, Sumartojo 1993, Weise *et al* 1994), there remains a fundamental gap in our knowledge of treating and caring for this group of patients.

2.17 Interventions to Promote Adherence

2.17.1 Outreach Assistance

Homeless people may refuse treatment for a variety of reasons such as mental illness, substance misuse, or their intricate and complex living situation. It is in these cases that outreach teams have been a valuable method of persuading patients to accept help. The role of the health professional in these teams is to motivate the individual to come into a treatment centre or their primary health care unit, or possibly to bring the treatment to the person on the street (Ormerod *et al* 1994). However, this approach is often slow and time consuming and may not be cost effective (Barnes, 1996). Nonetheless, McMurray-Avila *et al* (1998), argue that health professionals need to establish trust and rapport between themselves and the homeless individuals. As such, outreach assistance may be a valuable way to access and work with this hard to reach and hard to treat group.

2.17.2 Tuberculosis Screening

Screening for TB by way of a chest X-ray is a frequent technique in the UK, although Stevens *et al's* (1992) literature review highlighted that X-ray screening alone failed to identify those at risk from pulmonary TB. Nevertheless, a four-year retrospective study indicated that if X-ray screening had been incorporated this would have raised the detection rate of TB (Ramsden *et al* 1988).

The screening of homeless individuals for TB is available in some areas of London but a study funded by the homeless charity Crisis, stressed that screening should be encouraged through the introduction of incentives (Citron *et al* 1995). By using a survey as a method of data collection, Citron *et al's* (1995) study was able to gather a large amount of data inline with mass screening of homeless people. However, the study was constrained in its methodological ability to gather rich data from a qualitative angle, which would have been beneficial in exploring the important issues raised from the survey. Although the study had limitations, it did have a significant impact on the management of TB in the inner cities of the UK. The scarcity of research in this area has given this study increased face validity.

A more recent London based study, evaluating the effectiveness of the Mobile X-ray Unit (MXU) identified 15 cases of active TB in the first six months of its implementation. The research found that the MXU was beneficial in preventing the onward transmission of TB through re-establishing contacts that were lost to follow-up by health services (Terence 2005). Active TB case diagnosis with the MXU suggests it to be clinically effective in the hard to reach populations. Initial cost estimates indicate it to be good value for money. However, the study found that there was a clear need to strengthen outreach assistance in most London areas. Of particular concern was a high loss to follow-up (from TB clinics) without evidence of follow-up investigation (Terence 2005).

2.17.3 Monetary Incentive & Support

Volmink & Garner (1997) reviewed five random control trials (RCTs) in the UK on strategies to improve adherence. Interventions examined were reminder letters, monetary incentives, health education and intensive supervision from staff. All interventions tested improved adherence, with monetary incentive the most effective.

Tulsky *et al* (2000) and Pilote *et al* (1996) conducted RCTs to test two interventions aimed at improving medication adherence for TB in the homeless. The findings of these two studies again suggest that medication adherence was higher with monetary incentive and support from health professionals, than with other interventions in the control groups. Tulsky *et al's,* (2000) RCT established that living in a hotel or apartment at the start of treatment indicated medication adherence and thus completion of treatment. Thompson *et al's* (2001) systematic review supports these findings and suggests that good housing can have a fundamental effect on health improvements. Giuffrida & Torgerson's (1997) review of RCT studies, also found that financial incentives increased patient's adherence to health care treatments. Ten of the 11 studies reviewed showed improvements in adherence. Although this is considered a small number of reviewed RCTs, the authors had excluded a significant number on methodological grounds. Haynes *et al's* (2002) systematic review summarised the results of 17 RCTs that measured both adherence and clinical outcomes. This secondary study supports the view that even the most effective

interventions did not lead to large improvements in drug adherence and treatment outcomes. However, two of the studies demonstrated that explaining to patients about adverse effects of treatment improved adherence. The findings reflect those of Calder *et al's* (2001) study, which found that there was a poor level of knowledge of the side effects in patients with poor medication adherence.

2.17.4 Direct Observed Treatment

DOT has been recommended by both the National Institute for Health & Clinical Excellence (2006) and the World Health Organization (1999) as a strategy to improve treatment adherence and studies have shown that its use reduces the burden of TB and drug resistance (and MDR-TB) worldwide (Walley *et al* 2001, Wilkinson *et al* 1997, Chaulk *et al* 1995).

DOT denotes that a health professional (or other) observes the patient swallowing the medication (World Health Organization 1999). This guarantees that a TB patient takes the correct drug, in the correct dose, at the right times (Maher *et al* 1997) and is used to increase adherence to treatment and completion of treatment.

Chaulk *et al* (1995) conducted a descriptive study using an ecological design to evaluate community-based DOT for TB control, the results of the study also found that the population showed a dramatic decline of TB following implementation of community based DOT. In addition Volmink & Garner's (2002) systematic review assessing the effects of DOT, suggest it is the most effective intervention in improving adherence and restoring TB patients to health. However, within the body of literature, it is clear that there is disagreement and conflicting evidence on the benefits of DOT. For instance, a research trial in Pakistan showed high default rates in all the interventions including DOT (Walley *et al* 2001). A study undertaken in South Africa also demonstrated high default rates in both those on DOT and self-administered treatment (Zwarenstein *et al* 1998). Volmink & Garner (2001) in a review of randomised and quasi-randomised trials comparing DOT to self treatment found no evidence that DOT improved treatment completion (although later in their 2002 paper these authors found DOT to be effective).

Farmer & Yong Kim (1998) acknowledge that the World Health Organization's policy on DOT has been effective but challenge the World Health Organization's claim that multi-drug resistant TB would cease to exist if DOT were to be established widely (Farmer & Yong Kim 1998, World Health Organization 1999). This argument is underscored by several authors who found that in other countries in which DOT was introduced rates of multi-drug resistant TB had remained either steady or increased. This indicates that DOTS is not effective in treating the more serious MDR-TB (Mitchison & Nunn 1986, Espinal *et al* 2000, CDC 2004, Tupasi *et al* 2003, Farmer & Kim 1998).

Consequently, a DOT-plus strategy was introduced in which patients are treated with second-line and third line drugs, and provided with an individualised and directly observed treatment regime (Farmer & Kim 1998). In the Farmer *et al* (1998) case study of impoverished TB patients in the slum areas of Peru, a community-based effort of DOTS-plus was initiated. The authors provided individualised treatment for more than 50 patients with longstanding TB disease. Most of the cohort was resistant to all four of the drugs used in Peru's TB programme. With intense individualised treatment regimens (community based), all of the patients became 'smear negative'- no evidence of tubercle bacilli on microscopy. In more than 85 percent of patients, results of smears and cultures remained negative a year into treatment. In addition, a study based in the United States compared DOTS with DOTS-plus among MDR-TB cases found that fewer deaths would occur under DOTS-plus (Sterling *et al* 2003).

Numerous quantitative research studies have been conducted in the area of TB treatment and interventions and many have reported the value of DOT as an effective tool to improve treatment, maximising cure, and reducing the risk of drug and MDR-TB resistance (Sterling *et al* 2003, Caminero *et al* 1996, Goodburn & Drennan 2000, Wilkinson *et al* 1997, Chaulk, *et al* 1995). However, in the UK, a survey of TB nurses at London chest clinics found that less than half of the TB services used DOT and when it was used, it was implemented as a last measure for non-adherent patients (Goodburn & Drennan 2000). It is important to stress the recent findings of the Pan-London study that found that most non-homeless TB patients are not infectious, have

access to health services, complete treatment and are cured without DOT. By contrast, homeless people were found to be at greater risk of poor adherence and loss to follow up (Story *et al* 2007). UK guidelines state that 17-23 percent of patients should have had DOT from start of treatment. Its use is especially recommended for homeless people and those unlikely to adhere. However, Story *et al's* (2007) research found that only 2.2 percent of all patients, and 2.5 percent of street and hostel homeless, were started on DOT. The study also showed that DOT use varied widely by TB centres throughout London (Story *et al* 2007). These results support Goodburn & Drennan (2000) UK survey findings, emphasising the lack of implementation of DOT by health professionals to vulnerable groups such as the homeless.

2.18 Conclusion

In summary, evidence suggests that homeless people have diverse social and psychological problems and are especially vulnerable to TB. Homeless people form a complex group of individuals who experience problems in accessing health care and are less likely to adhere to TB treatment. TB continues to be a serious problem among the homeless and the issues of poverty and social exclusion exacerbate transmission and complicate treatment.

The majority of studies on TB have focused on treatment interventions such as DOT and have not included homeless people within their samples. To date most of these studies have been based on medical treatment, mainly quantitative in design, and have not focused on the issues of homelessness in any depth. The result is that very little is known about the issues and problems surrounding homeless people in coping with TB and its treatment. Consequently, the existing body of knowledge is argued to be limited, offering only a surface view of the problem and offers no in-depth understanding the homeless-TB experience. With the thrust of research focused on treatment interventions and through a quantitative lens, little is actually known about the meaning of TB to homeless people and how they cope with it in their lives. Although there are clear indications in the literature that TB is associated with certain groups, little is currently known about them in London. The result is an indistinct and scanty picture, which requires clarification. The researcher became acutely aware that what was needed was a qualitative study capable of gaining this information.

PART II

…the experience of suffering, it's often noted, is not effectively conveyed by statistics or graphs…

the weakness of such analysis is of course their great distance from personal experience.

(Farmer 2005:31)

CHAPTER THREE - METHODOLOGY

3.1 Introduction

The chapter begins with a presentation of the research question and the aims and objectives of the study. The discussion of the research process consists of the researcher's perspective and theoretical paradigm, including ontology, epistemology and methodology. It will identify key philosophical and methodological debates, which will clarify the framework underpinning the study. This is followed by an exploration of the research strategy, methodological cohesion, symbolic interaction and Grounded Theory.

3.2 Research Question

The research question has evolved over time. A review of the literature revealed that studies were limited to epidemiological data and TB interventions, which were entirely quantitative and without insight from homeless people. This is not surprising, considering that the majority of studies on TB have been published by the medical profession (mainly medical doctors). Although these clinical studies attempt to generate knowledge to improve treatment, for instance, on effective medication, they appear to have neglected to seek patients' views. It could be argued that the research focus has been heavily influenced not only by the characteristics of the discipline involved, but also by the desire for economic gain by commercial drug companies (Bowling & Ebrahim 2005, Bowling 2004).

The current study's qualitative design, focused on the homeless-TB experience, will address some of the gaps found in these other studies. In gaining a homeless service user perspective, new knowledge and theory can be generated which should provide health care professionals with a better understanding of the issues involved in the treatment of homeless people with TB. Consultation with various health professionals and homeless experts further reinforced the need to engage with homeless TB patients. This cooperation has led the researcher to develop a model of care, sensitive to the needs of this vulnerable group.

To allow flexibility of exploration, the research question became broad enough to encompass the complexity of the research problem yet focused enough to direct the course of the study. The following are the research question, aim and objectives of the current study.

Question: What does having tuberculosis mean to homeless people and how does this impact their opportunities to complete treatment?

Aim: To understand the experience of living with TB and being homeless.

Objectives:

- To develop a substantive theory on the homeless experience of tuberculosis.
- To gain insight and knowledge on the experience of being homeless while diagnosed with TB.
- To understand how homeless people deal with issues of TB and homelessness.
- To identify factors that impact upon homeless people taking their TB treatment.

3.3 The Research Process

There are three interwoven activities that define the qualitative research process. Several terms are used to refer to this process. They include "theory, method and analysis, ontology, epistemology and methodology" (Denzin & Lincoln 2000:18). At the forefront of these labels exists the researcher's personal perspective, based on life experience and encompassing the multiple facets of gender, social class, culture and ethnic perceptions (Denzin & Lincoln 2000). The researcher's inquiry route is based upon a collection of structured concepts (ontology) that identify a series of questions (epistemology) that are then analysed (methodology) using a particular approach. These interrelated general research activities are placed and described by Denzin & Lincoln (2000) in five phases, outlining the conceptual and functional processes of

the research. Although the researcher did not use Denzin & Lincoln (2000) direct terminology, the aspects have been covered in this thesis. The five phases include:

Phase 1: The Researcher

Phase 2: Theoretical Paradigms and Perspectives

Phase 3: Research Strategies

Phase 4: Methods of Data Collection and Analysis

Phase 5: The Art, Practices and Politics of Interpretation and Presentation

Phase 1 features the role of the researcher and the history of the researcher, which may have had an impact or influence on the research process (see Section 3.3.1). Phase 2 concentrates on the three theoretical principles: ontology, epistemology and methodology (see Section 3.3.2). These approaches to knowledge formulate the manner in which the researcher views the research and affects the choice of research paradigm. Phase 3 addresses what is considered by the researcher to be the most suitable and capable research strategy in responding to the research question (see Section 3.4). Phase 4 explores the method of data collection and analysis (see Sections 4.4 and 4.5). Phase 5 covers the art of interpretation and presentation (see Chapters Five, Six & Seven) (Denzin & Lincoln 2000).

3.3.1 The Researcher's Perspective

The researcher's understanding of this subject developed from nursing experience undertaken on an infectious diseases unit at a London hospital. The decision to select this research topic arose from a particular event during a clinical placement, in which a homeless patient was admitted with TB. The patient had difficulties in adhering with drug therapy and frequently missed doses. Within the nursing team there appeared to be a lack of knowledge of the homeless condition and lack of expertise in establishing drug adherence in those circumstances. At the outset, the researcher knew little about homelessness and the concepts surrounding adherence.

Current literature presented the researcher with evidence suggesting that TB is more common within the homeless population, but could rapidly spread to the general public (McMurray-Avila *et al* 1998). TB treatment is complicated by problems associated with homelessness, which present obstacles to drug adherence.

Cullum (1997:4) argues that 'research makes a difference to patient care'. This study found that patients who received evidenced-based nursing care made 'sizeable gains' in behavioural knowledge, physiological and psychological outcomes' in comparison with patients who experienced routine practice (Cullum 1997). Bass *et al* (1993) notes that the majority of researchers conduct studies of the homeless due to consciousness of their plight; as is the case with the researcher. However, Bass *et al* (1993) claim that it is essential to report accurate findings, although they may show the homeless in a poor or negative light - emphasising the necessity for the researcher to be unbiased, despite awareness of the inequalities in health homeless people encounter. Nevertheless, nurses are seen to have the professional skills to deal with the challenges of caring for the most vulnerable in society and to confront inequalities in health care (Whitehead 2001).

3.3.2 Theoretical Paradigms & Perspectives

Recently, there has been a significant interest in the role of philosophical positions and paradigms for conducting research. A paradigm can be described as a school of thought, but is much more to the researcher (Parahoo 1997). A theoretical paradigm provides a structure for the research, influencing a number of factors, including the phenomena to be researched, the method and the means by which the data are to be analysed and interpreted (Parahoo 1997). While research can be carried out in a number of ways, these methods derive from diverse philosophical perspectives and paradigms. Identifying the research paradigms is dependent on recognising and acknowledging the researcher's stance in respect to the following queries:

- What is the nature of reality? (ontology)
- What is the relationship between the inquirer and the known? (epistemology)
- How do we know the world, or gain knowledge of it? (methodology)

Responses to these philosophical queries are formed by the researcher's beliefs of the outside world and how they act based on these beliefs (Denzin & Lincoln 2000, Proctor 1998). Recognising the research paradigm is vital in shaping the research approach of the inquiry. In order to distinguish the research paradigm pertinent to this investigation, the researcher's perspective is summarised below in Table 1, and is discussed in the remainder of the chapter (Denzin & Lincoln 2000):

Table 1: Researcher's Perspective

Philosophical Position	Naturalistic Paradigm
Ontology: A branch of philosophy that deals with the nature of being or the kinds of existence. *Question:* "What is the nature of the phenomena, or social realities, which I wish to investigate?" *Answer:* Social reality involves the meaningful actions and interactions of individuals **(phenomena= homelessness/TB)**	**Relativism:** Reality is multiple and subjective, constructed in view of individual's knowledge and experience. These realities are dependent on change and can be reconstructed as a consequence of up-dated knowledge and experience.
Epistemology: A branch of philosophy that deals with the nature, origin and scope of knowledge. *Question:* "What might represent knowledge or evidence of social reality to be investigated?" *Answer:* Knowledge of social reality is associated with our understanding of the meanings and motives that direct the actions and interactions of people.	**Subjectivist:** The construction of research knowledge develops according to the relationship and interaction between the researcher and participant, and researcher and data. Findings are the creation of the interactive process. Knowledge is subjective not objective.
Methodology *Question:* How is knowledge obtained? *Answer:* Knowledge is viewed as socially constructed. *Qualitative design*: Interpretivisim Grounded Theory.	**Interpretative:** ▪ Inductive process ▪ Flexible design ▪ Focuses on participant's experience rather than demonstrating facts or truth ▪ Interpretations are grounded in participant's experiences. ▪ Emphasis on narrative information and qualitative analysis.

3.3.2.1 Ontology

The importance of producing a rigorous qualitative study begins with an understanding of the essence of the enquiry. This is articulated in the form of a question (Denzin & Lincoln 2000, Proctor 1998), which asks:

> What is the nature of the phenomena, or social realities, which we wish to investigate?
>
> *Researcher's response:* Social reality involves the meaningful actions and interactions of individuals.

In attempting to address this question, the researcher must explore in-depth the nature of the research. It entails asking what the researcher perceives as the fundamental nature and basis of things in the real world (social world), otherwise known as the ontological position or perspective.

According to Mason (1996) ontology can be a challenging concept to comprehend, especially because the nature and essence of social realties appear to be so basic and apparent that it can be difficult to perceive what there is to conceptualise. It can be relatively perplexing to even give thought to the idea that it is possible to have an ontological position (instead of merely being aware of the ontological components of the social world), as this implies that there are perhaps various explanations of the nature and essence of social realities.

Thus, through the awareness of alternative ontological views, and by recognising that these views may highlight differing accounts of social realities, the researcher is able to draw a personal ontological perspective of the nature of the social reality. The researcher's viewpoint ought to be distinguished and acknowledged as such, rather than accepted as an apparent and universal truth, which can be taken for granted.

Mason (1996: 11-12) suggests that different ontological positions (outlined in Figure 1) can be used to construct views on the nature of phenomena or social realities.

Figure 1: Ontological Positions

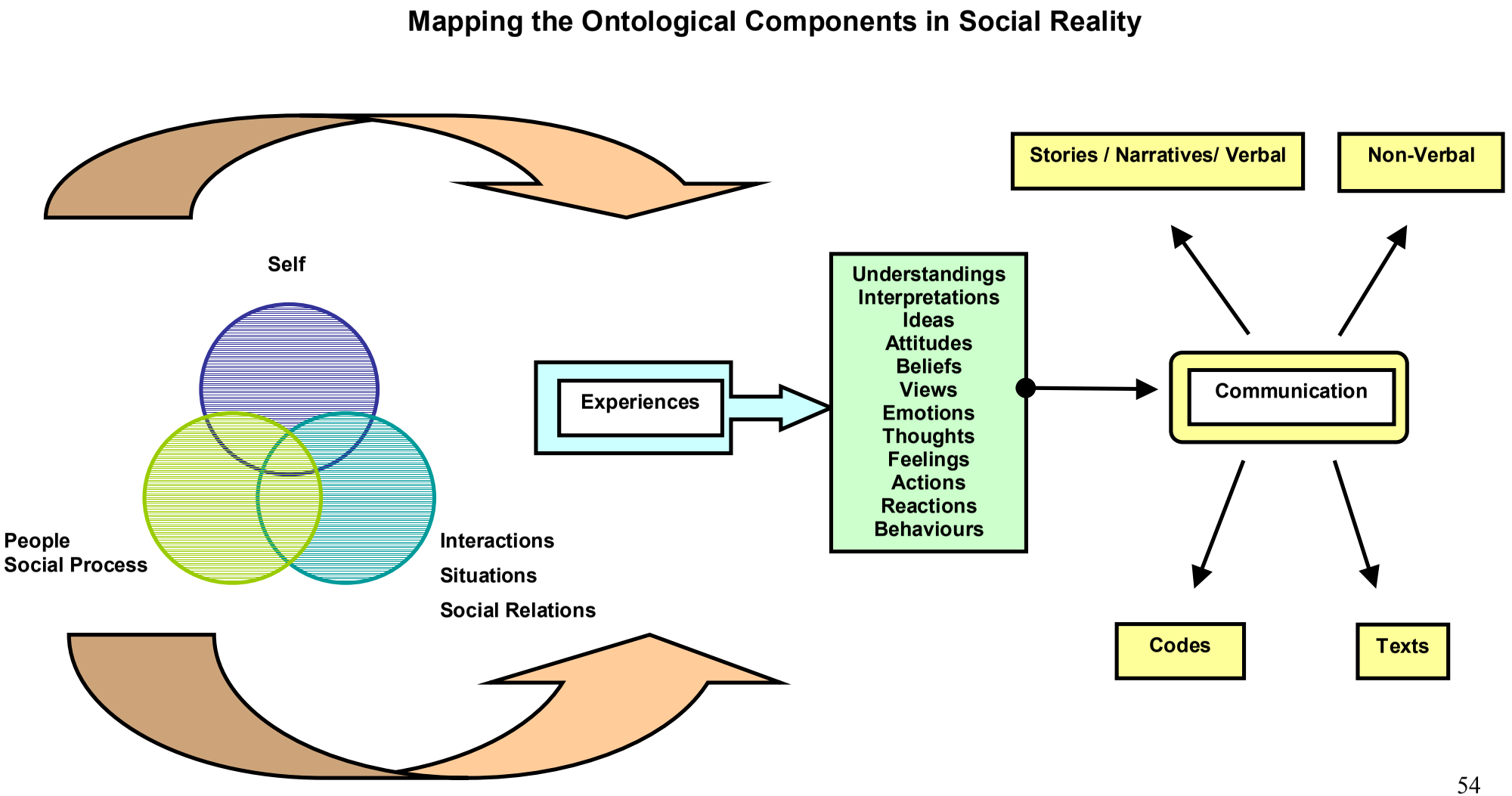
- "people, social actors
- bodies, subjects, objects
- minds, psyches
- rationalities, emotions, thought, feeling, memory, senses
- consciousness, subconscious, instincts
- understandings, interpretations, motivations, ideas
- attitudes, beliefs, views
- identity, essence, being
- self, individuals
- others, collectivities
- representations, cultural or social constructions
- experiences, accounts
- stories, narratives, biographies, evolution, development, progress
- texts, discourses
- words, codes, communications, languages
- actions, reactions, behaviours events
- interactions, situations, social relations
- social or cultural practices
- social processes
- rules, morality, belief systems
- institutions, structures
- cultures, societies
- empirical patterns, regularities, order, organisation, connectedness
- empirical haphazardness, disorganisation, chaos
- underlying mechanisms
- one objective reality, multiple realities or versions"

(Mason 1996:11-12)

Although Mason (1996) acknowledges that the above is by no means an absolute list of ontological components, it draws attention to the varying possibilities incorporated by the social world, with implications for differing experiences of social reality.

The researcher's own ontological position, describing her views of the very nature and essence of the social world, is illustrated in Figure 2 below.

Figure 2: Researcher's Ontological Perspective



The diagram highlights the researcher's ontological position illustrating that reality is not a fixed entity, since it alters and develops, influenced by the individual's experiences and their social context. The impact of social context is fundamental because it is through our social interactions with others that our understanding and interpretation of the nature of reality is shaped (Cormack 2000).

A number of factors are believed to impact on experience. Figure 2 demonstrates that self, others, interactions, situations and social relations can all have an impact. These basic components influence life experience, which, in turn, relate to our understanding, ideas, attitudes and beliefs and these are expressed in communication. This notion of experience is at the heart of the researcher's mapping of ontological concepts of social reality. The two fundamental factors that have shaped the researcher's belief system are that experience is something that is subjective, and consequently an individual phenomenon for each person. Therefore, there are multiple realities. This position is said to be a relativist ontology, which encompasses and embraces an Interpretivist paradigm (Mills *et al* 2006).

The researcher recognises that different versions of ontology can compete with one another. Several of the components in the list previously mentioned, and the differences among them, are vigorously challenged and opposed by those with conflicting ontological perspectives. For example, "subject and object, mind and body, rationality and emotion, thought and feeling, nature and culture" is an age-old philosophical debate (Mason 1996:12). The key debates will be explored later in the epistemological section of this chapter (see Section 3.3.2.2).

A number of the ontological components listed are perhaps more in line with the qualitative research methodology and the researcher's ontological perspective is consistent with the qualitative methodology. It encompasses ontological components such as social processes, interpretations, social relations, experiences and understandings, which Mason (1996) considers particularly well matched to the qualitative methodology.

The poststructuralist would challenge the researcher's ontology, particularly the element of expressing this experience through communication (Figure 2). The poststructuralist's stance supports the belief that there is by no means a lucid interface into the internal life of an individual. They propose that a researcher cannot appreciate the intricate inner life of an individual, and that no real insight can be obtained because of the influence of the researcher's "language, gender, social class, race and ethnicity" (Denzin & Lincoln 2003:31). Furthermore, individuals are seldom able to provide full explanations of their experiences and all they can offer are their personal accounts or narratives, which may be incomplete and thus only partial to the reality of the phenomena.

Various authors claim the benefits of applying a multi philosophical approach when undertaking research, as the only resolution to addressing the philosophical predicament discussed above (Cupchik 2001, Knight 2002, and Denzin & Lincoln 2003). Consequently, the researcher will deploy a range of interconnected approaches to effectively elicit the experience of the homeless individual with TB. Hence, the researcher proposes a philosophical framework of an Interpretivist ontological paradigm (multiple realities - ontology), a subjectivist epistemology (knower and respondent co-create understandings), and a qualitative set of methodological procedures, utilising the methods of Grounded Theory (Denzin & Lincoln 2003). These epistemological and methodological approaches will be elaborated and explored later in the chapter.

It is important to note that at this stage the researcher is only able to illustrate a basic ontological perspective. The researcher considers that to answer the ontological question (what is the nature of the phenomena?) fully at the beginning of the research would not be viable, since it is the intention of the research to address this very issue (the phenomena of TB and homelessness). It is also argued that to try to answer ontological questions regarding the nature of the phenomena or social reality could influence, and thus bias, the research through speculative assumptions based on the researcher's own convictions. It is important to be aware of one's ontological position, as this can support and reveal the most appropriate methodology for

establishing a suitable design for the research. As a result, what has been presented is the researcher's ontological position, which in itself was an important means to raise the researcher's level of awareness of the nature of phenomena.

3.3.2.2 Epistemology

The researcher's epistemological perspective is based on the answer to the following question (Denzin & Lincoln 2000, Mason 1996):

> What might represent knowledge or evidence of social reality to be investigated?
>
> *The researcher's response*: knowledge of social reality is associated with our understanding of the meanings and motives which direct the actions and interactions of people.

The answer to this question is intended to assist the researcher to discover the type of epistemological position that the research will convey and apply.

There are different approaches to the nature of evidence and knowledge, which prompt specific and clear-cut questions concerning the collection and generation of data (Denzin & Lincoln 2000, Mason 1996). A researcher's epistemology is essentially their theory of knowledge and relates to the principles and rules by which the researcher decides how phenomena can be known and discovered (Krauss 2005). Consequently, epistemological questions direct the researcher towards an understanding of those philosophical issues that influence their view of what may be accepted as evidence or knowledge of phenomena (Krauss 2005, Cormack 2000).

The concept of epistemology enables the researcher to reflect upon the research in a different way than ontology (Krauss 2005). However, the relationship between epistemology and ontology is apparent. If social reality consists of the experiences and understanding of people, then knowledge of reality will be knowledge of those experiences and understandings (Cormack 2000, Krauss 2005). An example of this

epistemological position is seen in the research approach to this study, which aims to discover the reality of TB experiences among homeless people, through a means of "telling it as it is". However, for the researcher, "telling it as it is" involves gaining knowledge of the experiences, understandings and motives of the participants (Charmaz 2002, Cormack 2000). The researcher's ontology and epistemology is therefore based on the position that as individuals interact, they create their social realities and develop meanings about these events in their lives. (Agincourt-Canning 2006). The researcher will aim to understand the social reality from the individual's perspective (Krauss 2005), through participants' subjective reality by applying a qualitative, Interpretivist Grounded Theory methodology.

Nonetheless, the researcher is required to have an awareness of the different philosophies that underpin research methods. Proctor (1998) recommends that researchers should become acquainted with the two different philosophies of positivism and interpretivism, as these paradigms locate and formulate the methodological rationale. To provide a backdrop and context to what is considered pertinent knowledge to the current study, it would be pragmatic beforehand to refer to the background and central aspects of positivism and interpretivism which will be considered within the following text.

3.3.3 Locating & Establishing Paradigmatic Position

It is unproductive to merely debate qualitative against quantitative methods because selecting appropriate methods is foremost a question of philosophy (Hegelung 2005). Discussion of suitable methods requires a consideration of philosophical traditions: of positivism and interpretivism (Crossan 2003, Silverman 2001). Thus a more in-depth exploration of the philosophical debates about objectivity and subjectivity is central to understanding one's epistemological stance. Out of this debate should arise a suitable methodology for the current study (Hegelung 2005).

The theoretical paradigms, which provide the basis for research, conventionally extend from positivist to interpretivist, there is an underlying discrepancy in the basic philosophies with reference to appropriate data and the way these can be identified

(Denzin & Lincoln 2000). This debate between positivism and interpretivism is essentially an epistemological question of how we come to knowledge or truth (Whoolery[11] 2002). Both paradigms are important within the field of medicine, health care and nursing research. However, there is no true or untrue paradigm; the paradigm chosen is dependent on the type of research to be undertaken, and above all, on the researcher's perspective and the research question to be addressed (Denzin & Lincoln 2000, Mason 1996).

Traditional science arises from the philosophy of positivism, which was developed from the critics of metaphysics. Advancement in the natural sciences, particularly physics and chemistry in the mid-18th century, directed sociologists to the assumption that the quantitative methods of science could be similarly applied to the study of human behaviour. Positivism claims that the only valid knowledge is scientific knowledge, originating from Enlightenment theorists such as Pierre-Simon Laplace, who considered human beings as the principle instrument in the development of scientific knowledge rather than religious interpretations.

In the 19th Century, positivism developed from the philosophical beliefs of Auguste Comte, John Locke and David Hume who believed that there was little if any methodological difference between sociology and natural science, and that social science was controlled by the laws that governed the laws of physics (Crossan 2003, Robson 2002, Parahoo 1997). Positivism is an approach to the generation of knowledge that is distinguished by the search for one truth; it is dependent upon a detached, objective researcher and a rigorous approach (Kennedy & Lingard 2006).

In the 20th Century, positivism was expanded upon and became post-positivism. The development of post-positivism centres on the need for reason that transcends from theoretical statements (hypotheses) to form a logical conclusion through deductive thinking (Crossan 2003, Robson 2002, Parahoo 1997). Post-positivism adheres to the belief in one single reality but maintains that the whole truth is never fully understood, but is approached progressively through the processes of research. The

[11] Whoolery here refers to Matthew Whoolery and not the researcher, Magdalena Whoolery.

post-positivist paradigm thus offers those researchers looking at questions involving complex social and cultural phenomena an approach to research, while upholding the positivist loyalty to objectivity (Kennedy & Lingard 2006).

The dominance of positivism continues, and has a number of consequences for health and social research (Crossan 2003, Parahoo 1997). This ascendancy is essentially methodological and calls for research to be quantitative. Although quantitative research should not be mistaken for positivism, it is important to appreciate that quantitative studies do apply positivism's philosophical beliefs of reductionism, determinism and deductivism (Parahoo 1997). What is fundamental is that positivism relies upon objectivity of data collected by sensory observations. Quantitative research characteristically takes on a form of empiricism and can depend on subjective sources from participants. Reductionism demands quantitative researchers reduce multi-dynamic phenomena into simple components that can be accurately measured. The deterministic component relates to the concept of 'cause and effect' or fact finding to explain behaviour. The deductivist element relates to hypothesis testing. These elements of positivism within quantitative methodologies have a consequence which calls for objective measures that do not value the researcher, their beliefs or motives. In other words, the research is thought to be independent of any bias derived from the researcher (value-free) (Crossan 2003, Parahoo 1997). Positivism became the dominant paradigm within health and social research, but its presence in real world research has been increasingly confronted and contested by supporters from other paradigms, particularly those from interpretivism (Denzin & Lincoln 2000). Currently those in disciplines such as nursing and sociology have called for research methodologies which can provide insight into the experiences of how individuals live (Burrows 2000).

3.3.3.1 Paradigm Choice

For the purpose of this research, interpretivism provides the more appropriate theoretical, methodological and practical methods for the study. The main subjects of debate between positivism and interpretivism are centred on objectivity versus subjectivity; determinism versus meaning; deductivism versus intuitivism; researcher

bias and reflectivity. The consideration of such debates has led the researcher towards interpretivism because it provides a suitable research strategy in its epistemological approach to the experience of homelessness.

3.3.3.2 Objectivity versus Subjectivity

The subjective or objective nature of reality is at the heart of philosophical debates, with persuasive arguments to support both concepts (Robson 2002, Denzin & Lincoln 2000, Mason 1996, Parahoo 1997). As mentioned earlier, the positivist paradigm views the world in an objective manner, maintaining that scientific methods can essentially measure a phenomenon in a quest to predict and explicate causal relationships among key variables (Bowling 2004). The positivist method asserts that it can control bias and has the ability to generalise findings. Primarily, the emphasis is on statistics and generating hypotheses, while discounting the experiences of individuals (Richardson 1998). Positivism has presided over the research community as the dominant paradigm, and because of its ability to generalise findings it has been enthusiastically adopted in the medical field. This is most prominent in the area of TB research (Ammassari *et al* 2000, Bhatti *et al* 1995, Calder *et al* 2001, Caminero *et al* 1996, Chaulk *et al* 1995, Chaves *et al* 1997, Hernandez-Garduno *et al* 2004, Mitchison & Nunn 1986, Pilote *et al* 1996, Salomon *et al* 2000, Zwarenstein *et al* 1998).

The researcher would argue that this quantitative approach has resulted in an over-emphasis on disease and treatment interventions, rather than the meaning of the disease to individuals. Therefore, the researcher considers it necessary to start with an alternative approach in which the focus is on understanding the phenomenon of being homelessness with TB through a subjective lens rather than objective means. This standpoint is highlighted in the following exploration.

Positivism's premise of reductionism comes from the belief in the concept of objectivity, which assumes that there is an 'objective truth', discovered through bias-free enquiry. The traditional epistemology of objectivity asserts that the understanding of the world is separate from thought, action and language. Objects in

the world are perceived as real, benefiting from a reality, non-aligned to human self and human activity, which is, itself, insignificant and unimportant to the objective make-up of the world external to the individual (Richardson 1998).

The concept of objective reality is vigorously challenged by interpretivists, who argue that objective truth is a naïve and an unviable notion (Robson 2002, Denzin & Lincoln 2000). Interpretivists endorse the notion of the subjectivity of perception and maintain that research information acquired is not value free, but subject to the influence of internal (individual, self, being) and external processes (society, organisation, family, culture) (Burnyeat 1982, Guba 1990).

Interpretivists firmly believe that knowledge is an outcome of subjective constructions within individual minds and distinctive differences occur as a consequence of social experiences and interactions (Goodman 1984). This means a variety of versions of the world are constructed. Therefore, researchers are unable to obtain an exact representation or depiction of the world. Interpretivists argue that knowledge and truth are the result of perspective; hence all truths are relative to some meaning context or perspective (Schwandt 1994).

In this view, what is perceived, while true for the perceiver, can and will change with variation in the perceiver and perceived. An analogical illustration is in the example of the experience of post-operative pain. Although two individuals may have experienced the same operative procedure and post-surgical treatment, it is acknowledged that the experience of pain is subjective: "it is whatever the patient says it is (pain)" (Lilley *et al* 2005:147). One individual may experience the phenomenon of pain as agonising but another may perceive the experience as slight pain (Lilley *et al* 2005). In supporting this notion, knowledge is regarded as a subjective view of perception and, therefore, objective truth is unattainable (Russell, 1990). In concurring, Crossan (2003:51) argues that:

> Humans are not objects, and are subject to many influences on behaviour, feelings, perceptions and attitudes that positivists would reject as irrelevant and belong to the realms of metaphysics.

A notable example of positivism's influence in research can be found in the discipline of psychology, where quantitative methods are used to establish objective truth. Whoolery (2006) explores the above concept of objectivity and subjectivity though his work in questioning psychology as a coherent science. Whoolery (2006) confronts the basic assumption that through scientific insight human life and behaviour can be entirely understood and appreciated. He asserts that "we cannot comprehend people as we comprehend objects…humans cannot be understood in the same way as we understand a computer or a rock" (Whoolery 2006:2).

Citing the philosophical work of Levinas (1996), Whoolery (2006) proposes that to genuinely understand an individual, it is important to understand them with love and empathy. Because human beings cannot be understood in an objective way, an empathetic approach enables the researcher to come to a closer understanding of the person. Whoolery (2006) suggests that, if the intention of the psychologist is in fact to embark upon understanding an individual, he can in no way be conceptualised as an "object of research", since people are perpetually above and beyond an object. He leads the reader to the interesting notion that knowledge of a human being "must be paired with compassion, sympathy, and love", and he asks:

> How many times have you been told in a research methods course that to fully understand your subject of study, you must first love him? Not frequently, I imagine (Whoolery 2006:2).

Agreeing with Whoolery's illustration of the complexity of human beings, the researcher suggests that it is naive to assume that an individual could be fully understood through the positivist lens of objectivity. Consequently, the researcher's epistemology, as outlined earlier, is one which views knowledge as subjective, complex and differing from one individual to another. The Interpretivist approach promotes the necessary focus of meanings on the experiences of individuals, making sense through inductive analysis, by discovering commonalities in the data (Daff *et al* 2006).

Nonetheless, it is pertinent to note that the type of knowledge generated through the positivist paradigm is also vital, particularly for those in the medical field. Without it, treatment outcomes cannot be assessed (Knight 2002). The researcher would argue that while 'objective' knowledge is certainly valuable, when segregated from human experience, it is empty and futile unless some account is taken of the individual's insight, perspectives and meanings (Mol 2006). With reference to the present study, although it would have been possible to measure quantitatively a variety of factors in relation to homelessness and TB, unless the homeless-TB experience and its meaning to the individuals concerned is understood, the information acquired is inconsequential and limited, offering a surface view of the phenomenon. In other words, it is not enough to focus on effective treatments:

> The experience of living with a disease, is more than the disease itself, good care includes attending to the lived experience of patients (Mol 2006:405).

For this reason, the study will gather the perspectives of homeless people in a subjective manner, as these individual perspectives are vital in understanding the foundation of their behaviour. Therefore, the concept of an 'objective truth' in relation to the research problem is inappropriate.

The researcher claims that quantitative methods strip contexts from meanings in the process of developing quantified measures of phenomena, without taking into account human experience (Robson 2002, Denzin & Lincoln 2000). The positivist emphasis on objectivity, its denial of individual meanings and reliance on statistical data have established both positivism as a philosophy and quantitative methods as a tool of research as unsuitable to this particular inquiry (Bowling 2004, Denzin & Lincoln 2000, Robson 2002).

3.3.3.3 Determinism versus Meaning

Determinism maintains that for every cause there is an effect, and the majority of studies on TB apply the positivist approach of determinism by establishing cause and effect. Although there is a substantial body of evidence on effective TB treatments and interventions, these studies have ignored the 'meaning' of TB to these individuals. What is more, one of the groups most vulnerable to TB, namely

homeless people, has been ignored. Therefore, it is argued that a deterministic approach is inappropriate to this inquiry and an emphasis on meaning is required.

The Interpretivist approach is also suitable, as it does not intend to predict or control research (Robson 2002, Denzin & Lincoln 2000). This is because knowledge is argued to be derived from human experience, which is immeasurable and un-quantifiable - something which is not simply true or false, fact or fiction, but is changing and variable for each individual (Guba & Lincoln 1989).

It is the intention of the researcher to generate theory based upon the participant's subjective reality and constructed from participant's social knowledge, creating collective commonalities within the data. Knowledge is viewed as socially constructed and informed by a shared reality that is created by the social world and social interactions (Holloway 1997). This perspective is in keeping with the interpretivist approach, which concentrates on understanding the actions and meanings of individuals, centred upon an ontology that views the essence of reality as based upon individual perception. An interpretivist approach will be consistent with the researcher's epistemological position regarding the subjective nature of knowledge (Krauss 2005, Denzin & Lincoln 2000).

3.3.3.4 Deductivism versus Inductivism

In previous research, homeless people's experience of TB was not considered as evidence. Because of this knowledge gap, it became clear that a positivist approach of deductivism through hypothesis testing would also be inappropriate, because not enough is known about the subject to be able to test a theory by starting with a hypothesis. Therefore, an inductive methodological approach is required for this research. In other words, to generate theory from data (inductive) rather than theory testing (deductive) would be appropriate.

The aim of interpretivist research and the purpose of this inquiry can therefore be seen as related, since the fundamental feature of the paradigm is to develop

knowledge of a phenomenon outside of what was previously understood and accepted (Goodman 1984). Interpretivism focuses on the nature of knowledge and what it is to know, proposing that knowledge cannot subsist separately from the knower and that knowledge is associated with "experiential reality" (Von Glaserfield 1991:18). Interpretivism accepts that there is an objective reality, but emphasises that we cannot gain this knowledge, since objective realty remains unknown until it is experienced by ourselves. Such subjective reality is dependent on the individual's interpretation and influenced by their life experiences. The only objectivity that is accepted in interpretivism is 'corroboration' which is expressed as the ability to "predict on the basis of imputing to another person a scheme of acting or thinking that one has found to be viable for oneself" (Von Glaserfield 1991:21).

In this inquiry, it is hoped that constructions of reality will indicate similarities among participant's experiences through their personal interpretations. The concept of a corroborated reality is associated with Guba & Lincoln's (1989) 'joint constructions' and Glaser's (1978) 'theoretical saturation', in which research findings are based on data from participants, developed from their grounded constructions. The formulation of knowledge is constructed and developed as a result of a consensus, which can either affirm or discard previously held constructions. A corroborative construction of a phenomenon takes place as a consequence of individual's experiencing events in their lives that are related to contexts within their common view of the world, implying a similar experiential reality (Von Glaserfield 1991).

While 'purist' interpretivists may not accept that they share a commonality with positivists, Metcalfe (2005) argues that the two paradigms have an underlying relationship. His basic premise is that both epistemological paradigms utilise a framework of comparison, and that they are extensively present at their fundamental basis. For instance, positivist research applies statistics for comparisons: "variables are compared in regression, as trends, and against each other directly" (Metcalfe 2005:2). Interpretivists also apply comparisons from qualitative methods such as interviews in comparing different experiences to form commonalities and consensus:

"here the comparison comes in the form of how different what is said to what others say" (Metcalfe 2005:4). Therefore, there is a contradiction in the interpretivists' argument that they are at the opposite spectrum to positivism, since there is a similar methodological thread that goes through both paradigms.

Both positivist and interpretivist epistemology apply quantitative and qualitative methods (Crossan 2003), but it was argued earlier that the two paradigms represent different ways of approaching phenomena. Additionally, quantitative and qualitative methodologies share a commonality when examining phenomena in research, as both are deconstructive in terms of "disturbing the fabric of naturally unfolding episodes in the social world" (Cupchik 2001:5). In other words, in one way or another, knowledge is fragmented and is used as either an object or subject of inquiry. With a positivist/quantitative approach that knowledge is treated as objective material and the participant is viewed as an object to be investigated. On the other hand, the qualitative researcher's knowledge resides in the subjective experience.

Quantitative and qualitative approaches both operate with data, which involve fracturing the stream of events in the social world and concentrating on certain activities, statements, behaviour, individual response or themes. For instance, when coding an interview a qualitative researcher will focus on emerging topics and subjects. In other words, something becomes the subject or object of study (Cupchik 2001).

Both qualitative and quantitative approaches through their attempts to study objectively or subjectively direct selectivity, which can be a source of bias and distortion. The process of 'segmentation', whether by a quantitative researcher as a 'detached' experimenter in the laboratory or a qualitative 'engaged' interviewer, is continually selective. In the laboratory setting, selection is the act of manipulating and measuring variables. While in the interview setting, data is controlled by questions that are posed and environmental aspects. Hence, the 'raw' materials that represent data are continually shaped by the researcher (Cupchik 2001).

3.3.3.5 Reflectivity

In further examining the positivist assumption of objectivity, the researcher challenges the notion that 'objective truth' can be determined merely through participants, while ignoring the researcher as a fundamental component of the study. Advocates of qualitative research, however, claim that a researcher brings with them many things including, preconceptions, motives, principles and perspectives (Robson 2002, Denzin & Lincoln 2000). In addition to this, homelessness is an emotive subject (Kim & Mayfield Arnold 2004) and as a result, may affect the researcher and hence the data. In applying a qualitative, interpretivist methodology, the researcher acknowledges this influence has provided an open exchange with the reader, by giving a context for analysis and interpretation this will enhance the rigour of the findings (Crotty 1998).

It would be unrealistic to presume that a researcher can interact with participants and that data can be gathered with total objectivity, or to assume that the researcher is able to eliminate the effect of previous knowledge and experience. Because of this, it is important to acknowledge the researcher's ontological and epistemological ideology and it is argued that the findings of research are strengthened, as a result of reflectivity. The practice of reflectivity allows the researcher to identify and publicly acknowledge her position (Robson 2002, Parahoo 1997). The researcher's position was illustrated earlier in Appendix A and in Section 3.3.1.

It is interesting to note here, that the arguments against interpretivism generally relate to interpretivists' use of qualitative methods. Positivists claim that interpretivism is subject to researcher bias due to its use of qualitative methods and the closeness of the researcher to the participant and data. Interpretivists acknowledge this and address this issue by encouraging transparency in interpretations throughout the research process. Therefore, the use of reflectivity plays an important part in establishing validity (Chan 2005, Breuer *et al* 2002).

It is important to note that some critics such as Haskell *et al* (2002) and Parahoo (1997), suggest that not only is reflectivity a demanding task for the researcher, but it

can generate a relentless sense of paranoia about what the researcher brings into the research. Possibly this could be partly due to interpretivism's attempt to validate their research process. However, the irony of this view is that while interpretivism considers all knowledge to be, to a certain extent, a reflection of the researcher's subjectivity, the model against which the researcher's bias is determined is essentially objective and positivist (Haskell *et al* 2002). Thus, the researcher's bias is implicitly seen as a flaw or weakness, and in any case a worrying occurrence, since it allows the researcher to attain less than absolute objectivity (Guillaume 2002). As acknowledged earlier, an objective approach to this inquiry is inappropriate, but Haskell *et al* (2002) would argue, it is 'impossible'. In applying interpretivism, it is argued that while rigorous awareness of understanding researcher bias is important, it can present demanding and unjust concerns when interpreted through the lens of the 'logic of objectivity.' (Haskell *et al* 2002).

Agreeing with Parahoo (1997), the researcher suggests that reflectivity alone is not enough, since it does not eliminate researcher bias. It is proposed that bias should not always be viewed as a weakness, but as a potentially positive feature, because the researcher brings in an important element to the research, through opening meaningful connections in the data. A primary example of this is the fact that this researcher has chosen to conduct a study on homelessness and TB. It is argued that the very nature of this choice is influenced by bias. The researcher's bias, that is to say, what makes the relation to the research unique, should be recognised as an important aspect of the methodology and data.

The researcher can do a number of things within the research process to address potentially harmful issues of bias, such as, keeping memos, field notes, an audit trail and showing participants' transcribed interviews for purposes of validation and rigour (Mays & Pope 2000).

3.3.3.6 Interpretivism for the Study of Homelessness and TB

To understand participants' experiences of homelessness and TB, and to generate a reconstruction of their social world, it is vital to collect rich, in-depth descriptions

from the participants' social contexts. The interpretivist paradigm acknowledges the intricacy and complexity of the human experience and recognises the power that people have within themselves to determine and generate their own experiences and to learn from these (Mills *et al* 2006). In recognising the complexity of the human experience, interpretivism is a paradigm that can accommodate and support the researcher's philosophical position and research needs (Mills *et al* 2006). The researcher agrees with interpretivists' belief that reality is not objectively determined, but is socially constructed (Hussey & Hussey 1997). The underlying notion is that by placing people in their social contexts, there is greater opportunity to understand the perceptions they have of their own experiences (Hussey & Hussey 1997). In such research, the results of the inquiry are at all times guided and formulated by the communication and relationship between the researcher and the participant. By its nature, interpretivism promotes the value of qualitative data in pursuit of knowledge (Kaplan & Maxwell 1994). In essence, the Interpretivist paradigm is concerned with the uniqueness of a particular situation to the underlying pursuit of contextual depth (Myers 1997).

While interpretive research is recognised for its significance in providing contextual depth, results are often criticised concerning their robustness, referred to as research legitimisation (Kelliher 2005). These concerns are amplified in applying a qualitative design (Eisenhardt 1989, Perry 1998). However, Grounded Theory, as a methodology, has been professed as rigorous and robust in systematically developing theory from data. Furthermore, there is an inherent link between Grounded Theory and interpretivism (Mills *et al* 2006, Pickard & Dixon 2004, Guba & Lincoln 1989). The use of Grounded Theory will be discussed in the following section.

3.4 Research Strategy

3.4.1 Methodological Cohesion

Both ontology and epistemology influence our choice of methods (Proctor 1998). The use of theoretical triangulation or cross-fertilisation of ideas in qualitative designs can offer a more holistic picture and provide a better way of understanding the connections between theories and data (McClean & Shaw 2005).

Following a review of the various qualitative methodologies that could be applied to this study, such as phenomenology, ethnography and numerous others, it was deduced that it was important to select one which provided methodological cohesion. The researcher felt this would be achieved when the research aims fit the methodology and the ontological and epistemological position of the researcher (Morse & Richards 2002). This cohesiveness is argued to strengthen validity and reliability, which are the cornerstones for achieving rigour (Franchuk 2004).

Grounded theorists and phenomenologists both use in-depth, semi and unstructured interviews to collect rich, meaningful data and both are flexible methodologies (Polit *et al* 2001, Franchuk 2004) which could be applied to researching the phenomena of homelessness and TB. By way of comparison between these two approaches, the researcher will illustrate the most suitable methodology of the current study, which in her opinion is Grounded Theory.

Phenomenology is primarily concerned with discovering and understanding the meaning of individual and group lived-experiences of phenomena (Polit *et al* 2001). Grounded Theory is concerned with explaining a socially constructed process by presenting a substantive theory or model (Glaser 2002, Glaser & Strauss 1967). A phenomenological approach would focus the investigation on one aspect (Polit *et al* 2001) of phenomena of homeless people's experiences of TB. The researcher claims that this would not successfully address the research aim of examining homeless people's perspectives, their experience of having TB *and* develop a substantive theory (see Section 3.2). If the researcher used phenomenology, the study would thus lose validity, because it would not have addressed the second aim of theory construction. By using a Grounded Theory approach it will address the original research concern and thus provide validity for the study.

Although, like many qualitative methodologies, phenomenology provides rich description, it lacks a conceptual developmental tool (Franchuk 2004). The data analysis and theory-building characteristics of a Grounded Theory approach are methodologically cohesive with the aims of the research.

The researcher's choice of a qualitative approach certainly indicates an approach to knowledge construction based on the conceptualisations of those who live the experience and emphasises the value placed on their meanings. The researcher wanted to give a voice to homeless people who previously have been ignored and to empower those who are traditionally 'done to', meaning those homeless people who are told to "adhere" with their treatment (Young *et al* 2004).

In deciding upon the use of Grounded Theory in the study of homeless people with TB, the researcher evaluated the capability of Grounded Theory to recognise the importance of individual experiences and the impact of these upon their decisions. Grounded Theory also gives significance to people's interactions and, consequently, their interpretations of their social world (O'Callaghan 1998, Richardson 1998). In addition, Grounded Theory goes further than other qualitative methods such as phenomenology, because rather than simply describing the lived experience, the explanations it forms are authentically new knowledge and are applied to develop new theories about a phenomenon.

Within health care settings, these novel theories can be useful to health professionals, particularly in approaching and addressing existing problems in new and more effective ways. In Grounded Theory, simple explanations of experiences or situations are substituted by theoretical conceptualisation (Munhall 1989), which focuses on the interactional processes within individuals' lives in their social world. This notion resonates well with the researcher's goal of applying a methodology that underscores the empowerment of homeless people, who often do not have a voice in research, rather than simply presenting interpretations my means of descriptive explanations.

In summation, the justification for applying Grounded Theory is its value in developing conceptual explanations of complex phenomena and in providing rigour (Myers 1997, Urquhart 2001). Grounded Theory also provides a set of procedures for coding and analysing data, which keeps the analysis close to the data and provides for inductive discoveries about the phenomenon under study (Hughes & Jones 2004).

3.4.2 Grounded Theory

Grounded Theory is a process by which a researcher generates theory that is grounded in the data (Glaser & Strauss, 1967). Grounded Theory entails:

> …subsequent, sequential, simultaneous, serendipitous and scheduled…data collection and analysis with a number of stages including…collecting, coding, analyzing memoing, sorting and writing (Glaser 1998:15).

At every stage theoretical concepts are discovered, corresponding to the meticulous coding of data. The basic aim of Grounded Theory is the discovery of a core category attained by the grouping and integration of coded concepts under a distinct systematic process. According to Glaser (1998:132) "The discovery of the participant's main concern led to the core category (the resolving process)…" Categories are applied to elucidate the properties of the social processes being researched (Glaser & Strauss 1967, Glaser 1992). The generation of categories is grounded in the data and hence is not based on a preconceived theory or premise (Glaser 1993). Grounded Theory is a monotonous and recurring process whereby the researcher frequently returns to the data sources. This is to verify and confirm aspects of the emerging themes and to collect fresh data when necessary (Glaser 1998). This process is called constant comparative analysis. The central aspects of the subject are mapped through constant comparison of data and generate theory by gradual focusing (Glaser 1998).

Hughes & Jones (2004) point out that Grounded Theory has been mainly used in interpretive studies with qualitative methods, as it is the most appropriate paradigm (Hughes & Jones 2004). However, a misconception about Grounded Theory is that it is a purely qualitative method (Higginbottom 2004). Many researchers, have used Grounded Theory as a general methodology, applying it to both quantitative and qualitative research (Kennedy & Lingard 2006). Glaser (1998:11) maintains that "Grounded Theory stands on its own as a theory of method which yields techniques and stages that can be used on any type of data". Nevertheless, studies applying the interpretivist approach have become increasingly popular (Hughes & Jones 2004). Interestingly, Glaser (1998) points out that deductive research, in which the

researcher preconceives by starting with a hypothesis, is a rather simple and a straight forward research process; he asserts that inductive research is more difficult, and upholds the value of conducting qualitative-inductive research through the richness in conceptualised data (Glaser 1998). Grounded Theory is compatible with the researcher's intention of discovering the participant's main concerns and developing a theory explaining the processing of the problem (Glaser 1998). Glaser states that "discovering the main concern or problem of the participant is what socially organises the behaviour in the substantive area, hence the emerging theory" (Glaser 1998:117). There are a number of facets which make Grounded Theory and the interpretivist paradigm compatible. Grounded Theory, with its inductive roots has the ability to provide rich contextual theory (Myers 1997, Urquhart 2001); it appreciates the multiplicity in constructions of social reality, in the process of analytical analysis and the conceptualisation of data. In this study, the use of Grounded Theory was also justified on the basis that it recognises the important role that the researcher plays in the study (Hughes & Jones 2004).

Although it has been noted that conducting an Interpretivist study is more complex, Grounded Theory is one of the few methodologies that the researcher discovered which could guide her from the instant she entered the field to the writing-up phase (Glaser 1998). As discussed earlier, other forms of analysis have few tangible and solid explanations of how to carry out the research. Grounded Theory has the advantage of presenting the researcher with rigorous and systematic steps in theory development and appears to be one of the few models of analysis that has generated clear descriptions of how data should be analysed. These procedures and processes provide a set of guidelines for the method of data collection and analysis which are based upon rigorous steps for Interpretivist studies (Hughes & Jones 2004). This is supported by Urquhart (2001) who argues that:

> Grounded Theory is by definition a rigorous approach, it demands time, it demands a chain of analysis and the relating of findings to other theories. As it is an inductive, emergent method that is located mainly in post positivism, this means that researchers need to carefully consider their own philosophical position (Urquhart 2001:27).

There have been a series of papers that have criticised Grounded Theory for not specifying its theoretical underpinnings [12](Charmaz 1995, Clarke 2003, Dey 1999, Dey 2004). However, Klein & Myers (1999) maintain that considering a method as either positivist or interpretivist is fruitless because quantitative methods have been used in interpretive research and qualitative methods used in positivist research. Urquhart's (2001) philosophical assumption about Grounded Theory being post-positivist is inept, as Glaser has repeatedly stated that Grounded Theory (GT) is a general method, and should be used as such (Glaser 1998). Furthermore, Avis (2003) maintains that researchers do not need methodological theory to do qualitative research, asserting the value of a pragmatic empirical research philosophy where epistemology is separated from methodology. In agreement, Glaser argues for 'just doing' Grounded Theory and maintains that it is a method in its purist form; that to try and bind Grounded Theory to a philosophy dilutes and complicates its straight forward approach to research (Glaser 1998, 2004). Although Glaser recognises the importance Grounded Theory has played among qualitative researchers, particularly in the legitimising it as a rigorous method, he asserts, however, that "Grounded Theory was not developed to foster a qualitative ideology" (Glaser 1998:38).

It is most certainly the recognition and importance placed on rigour in the Grounded Theory method that has seen an enthusiastic up-take by qualitative researchers. As a research method, Grounded Theory (Glaser & Strauss 1967) has been increasing in usage in health studies and this is evidenced by the growing body of literature (Hughes & Jones 2004). It is one of the most commonly used research methods (Creswell 1998). World wide, Grounded Theory is the most cited method by researchers doing qualitative data analysis, according to database searches, Google, Medline, CINAHL, Psyclit and Econlit. In illustrating this, a simple Google search flags up 16,000,000 internet sites and papers using the term Grounded Theory (Accessed: April 30, 2006). Grounded Theory has traditionally and strongly been anchored to the social sciences, predominantly through Symbolic Interactionism (see Section 3.4.3), thereby influencing the disciplines of sociology and social psychology. However, the method of Grounded Theory has been adopted in other

[12] For a detailed discussion from Barney Glaser on the classic Grounded Theory method- "The Grounded Theory Perspective I & II" (Glaser 2001, Glaser 2003) can be consulted.

disciplines including research in education, business and nursing (Hughes & Jones 2004, Strauss & Corbin 1998). Interestingly, Strauss & Corbin (1994) stated that they regret that Grounded Theory could risk becoming popular and they were keen to point out the importance of theoretically sensitive and trained researchers (see Section 4.5.1) (Strauss & Corbin 1994).

Grounded Theory was developed originally by Glaser & Strauss (1967) as a method to facilitate the "systematic discovery of theory from the data of social research" and was initially introduced in The Discovery of Grounded Theory (Glaser & Strauss 1967, Glaser & Strauss 1978:2). The methodology was formulated in reply to the overpowering conviction held by positivist theorists that qualitative research was unscientific as it abandoned controlled experiments and seemed to welcome interpretation (Maijala *et al* 2003, Charmaz 2000, Johnson 1999).

Glaser and Strauss, while both sociologists, emerged from diverse settings and thus experience. Glaser was trained in quantitative research methods, and qualitative mathematics at Columbia University by Paul Lazarsfeld, a leader in quantitative methods (Glaser 1998, Strauss & Corbin 1998). Glaser was also influenced in theory construction by Robert Merton; particularly in theoretical coding, which Robert Merton learned from Talcott Parsons and others (Glaser 1998). Additionally, Glaser received training in explication of text at the University of Paris (Glaser 1998). On the other hand, Strauss was enriched by the Chicago school of thought, with the influential teachings of Herbert Blumer, Evert Hughes and Robert Park who trained Strauss in Symbolic Interactionism (Blumer 1969, Glaser 1998, Strauss & Corbin 1998, Charmaz 2001).

As Glaser and Strauss worked in partnership on a qualitative research study discovering patient's perceptions of dying, both individuals, and Glaser in particular, considered it was crucial that there be a detailed, systematic procedure of generating theory that was grounded in the reality of the social world. Grounded Theory was, therefore, developed and envisaged in an endeavour to acquire scientific rigour for qualitative research through this methodology (Kennedy & Lingard 2006).

3.4.3 Symbolic Interactionism

Grounded Theory's philosophical roots are partly influenced by Symbolic Interactionism, which was developed at the University of Chicago, where Strauss was a student of Herbert Blumer (Blumer 1969). It is important to emphasise that this is only one aspect of the Grounded Theory methodology, which was greatly influenced by the work originating from Columbia University (Glaser 1998). During collaborative research between Glaser and Strauss on "Awareness of Dying" (Glaser & Strauss 1965), Glaser describes the significance of symbolic interaction:

> I started learning [from Strauss] the social construction of realities by symbolic interaction making meanings through self-indications to self and others. I learned that man was a meaning making animal. Thus there was, it seemed to me, no need to force meaning on a participant, but rather a need to listen to his genuine meanings, to grasp his perspectives, to study his concerns and to study his motivational drivers (Glaser 1998:32).

In turn, Strauss learned about the constant comparative process from Glaser (see Section 4.5.8). The key aspect of the collaboration was the move away from impressionism influenced by the Chicago school's teachings and putting in its place theory grounded in data. As a result of the collaboration, the Grounded Theory methodology was developed (Glaser 1998:32).

Symbolic Interaction is the process of human interaction in the formation of meanings. People act on the basis of the symbolic meanings they find within any given situation and thus interact with the symbols, forming relationships around them. The goals of the interactions with one another are to create shared meaning. Language is symbolic, and is used to attach meanings to the symbols (Griffin 1997).

Symbolic interaction came from the work of Charles Peirce and William James (Griffin 1997) expanded upon by George Mead (Mead 1934). Mead became known as the Father of Symbolic Interactionism and was a professor at the University of Chicago. Mead believed that people talking to each other was the most human and

humanising activity in which people engage (Mead 1934, Griffin 1997). Mead's work was made prominent by his student Blumer, and it was he who coined the term Symbolic Interaction (Blumer 1969).

The Theory of Symbolic Interactionism is amalgamated by three core principles. These principles are denoted as meaning, language, and thought. These three principles led to conclusions about the formation of an individual's self-concept and socialisation into his community (Griffin 1997).

- The first principle of meaning states that humans act according to the meanings that they have given to people or things. Symbolic Interactionism holds the principle of meaning as central in human behaviour. It refers to people's social construction of reality. Once people define something as real, they assign to it real consequences. Therefore everyone's reality differs (Griffin 1997).
- The second principle is language, which assigns meaning through social interaction and facilitates the negotiation of meaning through symbols (Griffin 1997).
- The third principle is that of thought, which modifies each individual's interpretation of symbols. Thought, based-on language, is a mental conversation or dialogue that requires role taking, or imagining different points of view. Thought refers to how an individual's interpretation of symbols is modified by their own thoughts. With these three elements the concept of the self can be framed. The 'self' is, therefore, a function of language, without talk there would be no self-concept (Griffin 1997).

In summary, Symbolic Interactionism is an important perspective within sociology and psychology (Goffman 1969, Berger & Luckman 1967). It has been described as influential in the development of qualitative methodology (Robson 2002). However, Symbolic Interactionism is merely a philosophical position, rather than a research method. For methodological cohesion, the following section explores the Grounded Theory approach and its relevance to the current study.

3.4.4 The 'Glaserian' and 'Straussian' Approaches

Since the co-creation of their approach to theory development through research in 1967, Glaser and Strauss have taken different directions in further developing and evolving the pragmatic use of Grounded Theory. Their different paths led to what now is known as the 'Glaserian' and 'Straussian' versions of the Grounded Theory method (Stern 1994). This split has seen Glaser's model of theory generation taking on the original form (Glaser & Strauss 1967) where theory emerges directly and rigorously out of the data. This differs greatly from Strauss and Corbin's descriptive approach that encourages direct questioning (Strauss & Corbin 1990). As a result two distinct methodologies have emerged.

In "Basics of Grounded Theory Analysis" (Glaser 1992) Glaser presents a critique of Strauss & Corbin's (1990) use of Grounded Theory. According to Glaser (1992), his impetus for writing the book was to correct errors made by Strauss and Corbin in order to set "the average researcher back on the correct track to generating a Grounded Theory" (Glaser 1992:6).

The conceptualisation versus description discourse is at the heart of the debate between the Glaserian and Straussian methods of Grounded Theory. The difference in the method can be observed through the analysis of Strauss and Corbin's approach, which identifies the research question as a statement that indicates the phenomenon to be studied (Glaser 1992).

Conversely, the epistemological perspective of the researcher is that she should not preconceive what homeless people's main concerns are before she engages with them in the field. This is because this could seriously bias the study. From an interpretive perspective, Eisenhardt (1989) recommends that the researcher start with a broad research question. Consequently the researcher is inclined to agree with Glaser's (1978, 1992, 1998) approach, by stressing that the research problem itself is discovered through emergence as a process of open coding, theoretical sampling, constant comparison, and so forth (see Chapter Four). Essentially, it begins "with the

abstract wonderment of what is going on that is an issue and how it is handled" (Glaser 1992:22).

The most significant differences between Glaser's and Strauss' versions of Grounded Theory seem to hinge on both epistemological and methodological disparities between these approaches. Glaser's approach suggests that the theory should emerge naturally from the analysis with little forcing on the part of the researcher. Strauss's approach is more concerned with producing a detailed description of the individual's experiences. Strauss's emphasis on Grounded Theory retaining "canons of good science" such as replicability, generalisability, precision, significance, and verification (Strauss & Corbin 1990, Strauss & Corbin 1994) places him more within the positivist paradigm.

Although Strauss & Corbin (1990, 1998) present a more comprehensive explanation of Grounded Theory than the Glaser & Strauss (1967) original version (Miller & Dingwall 1997), it compromises the opportunity for the emergence of theory. Thus, for this research Strauss & Corbin's (1990, 1998) approach was inappropriate, as the aim of the research was to develop a substantive theory emergent from the research data. Furthermore, Glaser (1992) maintains that Strauss's approach of conceptual description is a forced result of influential procedures and goes against the original intention of Grounded Theory. Glaser (1992) contends that Strauss & Corbin's (1990, 1998) version, which he believes has deviated completely from the original, represents an entirely new methodology, which he labels as "full conceptual description" (Glaser 1992:6).

While recognising the validity of the two approaches, the differences between them are substantial. In examining both approaches, the researcher indeed found Strauss & Corbin methodology had diverted a great deal from the classic approach (Glaser & Strauss 1967). For instance, in reading Glaser & Strauss's (1967) early seminal work in "The Discovery of Grounded Theory", the researcher was later left perplexed by Strauss & Corbin's (1990, 1998) subsequent version; and in particular, their use of 'axial coding' (Glaser 1992, Kendall 1999). The issue being that axial coding was

not part of the classic Grounded Theory lexicon. In addition, other researchers in the literature have reported similar problems in using the Straussian coding system (Cronholm 2002, Kendall 1999 and Urquhart 2001). Although Strauss & Corbin's version has attempted to make a more undemanding method than the classic version, the method has been argued to force coding into various arrangements. Once more this is argued to impede emergence and is a preconceived coding system; in other words, to fit a predetermined framework. On the other hand, the classic Grounded Theory approach requires that the researcher code for every incident as prescribed in the classic text, therefore axial coding is argued to be unnecessary. The strict guidelines of Strauss & Corbin (1990, 1998) are argued to have a potential effect on the discovery of theory by attempting to assimilate it into a preconceived framework (Miller & Dingwall 1997). Hughes & Howcroft (2000) also warn against the rigid application of Grounded Theory for interpretivist research. Glaser (1978) agrees by expressing unease with the use of a set of guidelines or strict principles for the production of Grounded Theory, which he sees as restricting the process of emergence of theory and theoretical sensitivity. The classic Grounded Theory approach, on the other hand, provides the necessary guidelines and, at the same time, facilitates open and flexible analysis of data to generate the emergence of the theory (Douglas 2003, Goulding 2002, Locke 2001).

On deliberation the researcher considers that Strauss & Corbin's (1990, 1998) approach would be unsuitable because of its overemphasis on extracting detail from data by means of pre-structured procedures for full description, at the expense of theory development.

The researcher has selected the Glaserian approach, because the research was concerned more with the conceptualisation offered by the classic-Glaserian method than on the full description of Strauss and Corbin's model. The Glaserian approach strongly emphasises the abstract conceptualisations that go beyond people and time, yet its method is grounded in the substantive area (Eisenhardt 1989, Glaser 1998, Glaser 1978). This facet of Grounded Theory enables the researcher to avoid stating the obvious by telling health professionals and others what they already know

through description, but rather provides categories based on indicators and showing ideas, based on patterns, conceptually. These concepts enable health professionals and others to go beyond the confines of their own experience, modifying and relating the theory to other situations: because of its abstract nature, Grounded Theory transcends time and place. This feature achieves the researcher's goal for its result to be useful to both TB health professionals and homeless people. In other words, focusing on conceptualisation would contribute to new knowledge for health professionals in the field of TB. Thus, by following the classic Grounded Theory method, the researcher is able to contribute to new knowledge, grounded in data that has been enriched by emergent theory (Eisenhardt 1989, Glaser 1998, Glaser 1978).

There are a number of important aspects in conducting classic Grounded Theory. Two key features are that the researcher must not start with a theory to verify, disprove or expand; the second is that concepts emerge from the constant comparison process, between incidents and properties of a category (Urquhart 2001, Glaser & Strauss 1967, Glaser 1978).

Above all, Grounded Theory proposes that data should not be influenced by the researcher's own biases (Glaser & Strauss 1967). This is to say that to develop a Grounded Theory, a researcher should not have preconceived ideas, because the theory would not be grounded in the data, rather it would be a description of the researcher's bias. The position taken in classic Grounded Theory is not so much that a clean slate is necessary, or even desirable, because theoretical sensitivity and knowledge is important; the critical point is that the research does not begin with a theory to prove or disprove or influence the emergence of theory through this bias.

In Grounded Theory, when the researcher holds innate beliefs or biases, these can be captured as text and then analysed with other texts as another incident in the data, i.e., the process of memoing through constant comparison (Glaser 1978, Glaser & Strauss 1967). Glaser maintains that a concept has to earn its way into the theory.

The Grounded Theory process develops through the method of constant comparison. According to Glaser & Strauss (1967:113-14), the process assists the generation of complex "theories of process, sequence, and change pertaining to organisations, positions, and social interaction [that] correspond closely to the data since the constant comparison forces the analyst to consider much diversity in the data". Grounded Theory enables the researcher to manage issues of bias and preconceptions and provides a systematic approach that takes into consideration other literature and theories, but is not driven by it (Glaser & Strauss 1967, Urquhart 2001).

"All is Data" is a well-known Glaserian dictum (Glaser 1998:9). According to Glaser:

> It means whatever is going on in the research scene is the data, whatever the source, whether interview, observations, documents, in whatever combination. It is not only what is being told, how it is being told and the conditions of it being told, but also all the data surrounding what is being told. It means what is going on must be figured out... Data is always as good as far as it goes, and there is always more data to keep correcting the categories with more relevant properties (Glaser 2002:1).

However, Morse (2005) disagrees by arguing that data should be purposefully collected, and that not everything can develop into data.

A further critique of classic Grounded Theory is the belief that participants will tell the researcher what most concerns them. Charmaz (2004) disagrees with this assumption, stating that often participants are simply unable to. Charmaz (2004) illustrates this point with the example from her research with health professionals declaring clinical excellence as their priority, while in reality it is to maintain a safe financial basis. In concurring with Glaser, the researcher claims that individuals, if given the opportunity to speak in a safe environment, if assured confidentiality and if truly engaged with, will be able to articulate their concerns. What Charmaz (2004) has failed to recognise in classic Grounded Theory is the concept of "properlining", which ironically was first coined by grounded theorists (Glaser 1998). Properlining is the act of telling the researcher what the participant thinks the researcher wants or

should hear (Glaser 1998). When Glaser argues, "all is data" what he means in this case is that even the act of properlining should be coded for, hence documented and acknowledged, and is simply more data to analyse and understand (Glaser 1998).

In summation, it was important to select the approach most suitable to the aim of the current study, which essentially is to investigate homeless people's perspectives on TB, but importantly, to develop a theory grounded in their experiences. Therefore, the Strauss approach would not have met the research requirements, since it would only provide a descriptive tool for data collection (Glaser 1992). In fitting with the researcher's epistemology, Glaser's account (Glaser 1998, Glaser & Strauss 1967) would be more aligned with the epistemological position of the researcher.

3.5 Conclusion

This chapter examined the responses to the philosophical queries formed by ontology, epistemology and methodology. In order to distinguish the research paradigm pertinent to the investigation, the researcher explored the various elements to articulate the philosophical underpinnings of the study.

The methodology has several contributing approaches and thus applies methodological triangulation to address the requirements of the study and incorporates the researcher's paradigm. The methodology deploys a range of interconnected approaches, to seek an effective way to elicit the experience of the homeless individual with TB, to understand the experience of homeless people and the meaning of TB to these individuals (ontological query). Hence, the researcher presents a philosophical framework of an interpretivist ontological paradigm (multiple realities), a subjectivist epistemology (knower and respondent co-create understandings), and a qualitative set of methodological procedures, utilising the methods of Grounded Theory (Denzin & Lincoln 2003, Glaser & Strauss 1967, Glaser 1978, Glaser 1998). Although there are contentious debates surrounding these aspects, various scholars uphold the advantage of such an approach, and support its use in advocating the philosophical underpinning of a methodology (Cupchik 2001, Knight 2002, Denzin & Lincoln 2003, Procter 1998).

CHAPTER FOUR - METHODS OF DATA COLLECTION & ANALYSIS

4.1 Introduction

This chapter sets out the study design. Ethical aspects are explored, including ethics approval and the consideration of the vulnerability of the study population, as well as issues of support and safety. Incorporated in the ethics section are the subjects of informed consent, confidentiality and research funding. This is followed by an examination of the data collection methods, including discussions on access, recruitment, sample issues and interviewing. Next, the chapter outlines the data analysis used for the study, centring on the Grounded Theory approach. Finally, aspects of rigour are covered.

4.2 Research Design

As discussed in the previous chapter, the Grounded Theory method was selected because it fulfilled the criteria of theory generation in its capacity for conceptual development, and thus addressed the aim and objectives of the study. Grounded Theory has the capacity to systematically generate theory from data, and with its inductive roots, it provided a rigorous and unique approach to theory development. It also offered the researcher a methodical system to guide the research at each stage of the research process (Glaser & Strauss 1967, Glaser 1978).

The rigorous and systematic steps applied here allowed the theory to emerge from the data, as opposed to preconceived ideas or hypothesis testing (Glaser 1992). Grounded Theory is also appropriate, as there are no existing theories on the research topic and its use has provided a new perspective in a research area dominated by quantitative medical studies on TB treatment (Stern 1994).

The data in this study is comprised of 16 interviews with homeless people conducted by the researcher. According to Rogers & Bouey (1996), the most used data collection tool in qualitative research studies is the interview. These are categorised

into three types: structured interviews, unstructured interviews and semi-structured interviews (Burgess 1991). Initial conversations did not have a predetermined set of questions, because the interviews were designed to relax the participants so they could talk freely (Burgess 1991). Later questioning followed a semi-structured format enabling standardisation of certain questions. Although the researcher prepared an interview guide, questions changed depending on the emerging concepts. The flexibility of the qualitative design facilitated emergence.

Flick (1998) states that this interview style is widely used in qualitative studies. It was selected as a tool for data collection for three reasons. First, the method was appropriate for exploring meaning, experiences and perspectives of participants concerning complex and sensitive topics and allowed the researcher to follow leads to generate rich data. Second, the method provided flexibility and enabled the researcher to focus discussions and alter questioning to encompass the range of issues raised by individuals. Third, the approach was valuable in assisting the participant to understand questions, enabling the researcher to request clarification and to find further explanations, thereby enhancing validity. With the inclusion of some closed questions, the method ensured a level of standardisation, which enhanced reliability.

It was important that the well-being of participants should be considered (Royal College of Nursing 2004) and various scholars acknowledge that the application of a qualitative design imparts an ethically sensitive way of conducting research and regard its use as one of low risk of harm to potential participants (Maijala *et al* 2002, Ingleton & Seymour 2001, Clark 1998).

4.3 Ethical Considerations

4.3.1 Ethical Approval

The research underwent ethical review through the Multi-Centre Research Ethics Committee (MREC), at the Royal Free Hospital, London. The MREC application was successful, requiring two minor changes. The study fulfilled the requirements

and recommendations set out by the MREC review panel, and permission to conduct this study was obtained (see Appendix D). Ethical approval was also sought from Research and Development Departments at each of three host sites. The study was officially approved in March 2006, allowing data collection to begin.

4.3.2 A Vulnerable Population

It was especially important to consider the ethical issues as the research involved vulnerable participants. While there is debate on the ethics of involving vulnerable populations in studies (Moyle 2002, Usher & Holmes 1997), their contribution and engagement was vital, since the main aim of the research was to understand homeless experiences and perspectives, and gather their unique perspectives to develop a substantive theory. Furthermore, it was considered unethical not to include homeless people, as this hard-too-reach population had a right to evidence-based care. However, the study conformed to the relevant ethical and legal guidelines set by the United Kingdom Nursing & Midwifery Council (2004), the Royal College of Nursing (2004) and World Health Organization ethics guidelines (1995).

4.3.3 Support & Safety

In designing the study, consideration was given to the issue of support for participants. It was deemed important to conduct interviews only with participants who already had professional support in place, and it was therefore inappropriate to access participants directly, for example, from hostels, or rough sleepers on the street. Consequently, participants were accessed and interviewed at TB/chest clinics on NHS premises where a support network of health professionals existed.

The safety of the researcher was also an important consideration, and standard precautions were employed when conducting interviews with participants. First, all interviews were carried out on clinic or hospital premises, where staff members were present in the building, but not in the interview room. Prior to each interview, the researcher positioned the seating arrangements to ensure, if necessary, that an easy exit would be possible. Second, the researcher's supervisor knew the location and

whereabouts of the interviews, but not the names of the participants. The researcher also telephoned her father by mobile phone after the completion of each interview. Third, the inclusion and exclusion criteria, which are set out in Section 4.4.2.1, were designed to take account of health and safety issues and limit risk of exposure to MDR-TB. This was done by excluding patients with MDR-TB, and by ensuring participants were on treatment for at least two weeks prior to interview so they would be non-infectious. At no time did the researcher feel unsafe or threatened in the interview setting.

During the course of data collection**,** participants often discussed intense emotional experiences relating to: long histories of homelessness; intimate family problems; profound issues of isolation from support systems; and management of serious health and psychological problems. Collecting this data, especially through personal interviews, frequently involved hearing detailed accounts of their adverse life experiences. Under these conditions, the researcher benefited immensely, in debriefing with her supervisors, especially after difficult sessions of data collection in the field. The supervisors not only provided expertise in the research area but also gave their support through their experience of working with vulnerable groups. The researcher did not mention names or any details that would risk breaking confidentiality. The supervisors recognised the complexity and time-consuming nature of research with homeless people, and acknowledged that data collection and its analysis was both time consuming and challenging.

Although interviews did not deliberately delve into sensitive areas, at times some participants wanted to discuss matters that were distressing to them. Extreme care was taken to ensure confidentiality of information on sensitive issues such as housing status, drug abuse, mental and physical illness and criminal history. The researcher was conscious of her ethical obligation to refer participants to relevant professionals regarding any issues raised that required appropriate attention. This was explained in the participant information sheet. Although there were no particular incidents in which the researcher judged that a referral to the clinical manager was required, the participants were informed that where there were physical, social or psychological

problems that necessitated additional support, contact with an appropriate professional would be made.

4.3.4 Informed Consent

Gaining informed consent was vital, particularly because of the flexible nature of the qualitative design and the emergent nature of the Grounded Theory method. Bartunek & Louis (1996) emphasise the importance of repeatedly confirming informed consent. Neither the researcher, nor the participant, were aware in advance what would emerge from the interview situation. The researcher informed participants that events that unfolded could not be predicted, and checked that participants were consenting to the unfolding conversation. According to Bartunek & Louis (1996:58) "Informed consent is not something that can be handled once and for all at the beginning of a study," but is a continual process.

Prior to the request for consent, potential participants were given the opportunity to discuss issues and were provided the following information:

- the purpose and nature of the study;
- the study methods and what participation would involve;
- that participation was entirely voluntary and that they were free to withdraw from the study at any time;
- that only participants who are deemed capable of understanding what participation would involve, could participate in the study;
- that any decision they made to participate would not affect their current or future health care in any way;
- that their data would be kept strictly confidential and would only be used for the purpose of the study and future dissemination;
- that the research had been approved by MREC and that all research carried out conformed to strict ethical guidelines.

Participants had no less than 24 hours, and up to a week, from receiving information about the study to consider the information and their possible involvement. The study required a written consent signed by the participants themselves (see Appendix E). However, in accordance with the ethics guidelines from the World Health Organization (1995), oral consent was deemed acceptable from participants who were illiterate and could not read or sign informed consent forms. In this case, a literate witness was required to sign on behalf of the participant. The researcher ensured that witnesses were not part of the research team and that participants could choose their own witness. Although no participants fell into this category, arrangements were in place to address the needs of potential participants with these needs, if required. This ensured the inclusion of potential illiterate participants, and contributed toward equity.

Before interviews began, it was made clear to participants that the interview could be stopped at anytime if they felt emotionally disturbed by the discussions. This was also stated on the information sheet (see Appendix F). The need for respect and acknowledgement of the rights of the participants was always the researcher's primary concern and care was taken to protect participants from undue harm. All interviews were conducted by the researcher who had been trained in Grounded Theory methodology (New York 2003, New York 2004, San Francisco 2005) and who had received research training as a PhD student (2003 BCUC).

In a study such as this, the researcher must assess any risk or inconvenience of the study being undertaken against the anticipated benefits for participants and concerned communities (Royal College of Nursing 2004**)**. The risk of causing harm was considered small in comparison to the anticipated benefits of conducting the study. Furthermore, it was made clear that there were no direct benefits to participants, but that the findings might result in improvements to TB health care for homeless people in the future.

4.3.5 Confidentiality

According to Oka & Shaw (2000:15):

> Very few people would willingly express their most private details, opinions and emotions in public documents knowing that their names would be published.

Yet, in the interview situation, a number of the participants, described how they were keen to be named, because of their longing to be heard and identified. The researcher explained that confidentially was important to safeguard their identity, so they could speak freely without the fear of a breach of privacy. Furthermore, it was explained that confidentiality was an important requirement of research (Maijala *et al* 2002). Although respecting the participant's sense of empowerment the researcher knew that confidentiality was a vital requirement for credible research and thus maintained it throughout the research process (Oka & Shaw 2000).

The risk of breach of confidentiality was considered low for participants as all analysis of data was conducted by the researcher herself, in a secure office located at the research centre, on secure university premises. Transcribed interview data were anonymised by coding, using a numerical system and the participants' names were not stored on computer**.** Coding information was kept separately from computer records and stored in a locked unit**.** Data on computer was only accessed by the researcher through a personal password secured computer**.** All confidential data and other sensitive material were stored in a locked filing cabinet, on secure university premises. These materials could only be accessed by the researcher.

4.3.6 Research Funding

An explanation of the researcher's motivation is set out in Appendix A. During the course of her studies, she received a bursary of £6,600 pounds per year. This enabled basic subsistence. In order to further enhance the learning and research opportunities, the researcher sought additional funding. To this end, funding was secured from the Worshipful Company of Curriers, which awarded the Curriers' Company

Millennium Healthcare Bursary 2003. The £6,860 awarded enabled her to attend training courses and conferences relevant to the research subject and methodology. The funding was also used to pay the remuneration cost of £10 for participants volunteering in the study.

While seen as necessary, remuneration should be handled with care. Bruhn's (1998) U.S. study interviewing homeless families provided remuneration for participants. Bruhn (1998) gave research participants 50 dollars an interview. Considering the socioeconomic condition of homeless people, this was a considerable amount of money, and could be argued to be coercive and possibly unethical. The researcher was conscious of this issue, and took part in collaborative consultation with TB specialists and researchers who pointed towards an economic compensation that was set at a meaningful level to compensate for the participants' time. It was not so large as to become coercive. Therefore, the sum of £10 was offered to participants, not as an inducement, but as remuneration for expenses incurred, such as time and travel. Similarly, Croft-White & Parry-Crooke's (2004) homeless needs study, also provided £10 for their participants, which suggests that the sum provided was a just and appropriate amount.

4.4 Data Collection

4.4.1 Access & Recruitment

Health professionals who introduce researchers into the field are often called 'gatekeepers' (Oka & Shaw 2000). It is vital for a researcher to maintain a trusting relationship with gatekeepers, as they can make it easier for the researcher to build trust with the participants in the field. According to Oka & Shaw (2000), the first setback usually occurs during this process. As Lincoln & Guba (1985:257) point out, the building of trust is a developmental undertaking, and trust is not something that suddenly emerges, rather it is "a specifiable set of procedural operations", and something to be worked on. Trust is also fragile, and can take a long time to build. It can also be damaged quickly by an ill-advised action.

It is recognised that accessing vulnerable populations in research is complex, particularly the negotiation of entry into host sites (Anderson & Hatton 2000). The researcher anticipated this problem, and in her role as project co-coordinator for the Pan-London TB Study (see Chapter Two and Appendix B), she built relationships with health workers and managers in 30 TB/chest clinic in London. Gaining entry into these clinics was vital for undertaking the study, but was often a complex process that required on going communication (Bailey 1996). This early groundwork proved to be valuable in gaining the trust of managers and assisted in the incorporation of their perspective during early discussions of study design, increasing the potential usefulness and relevance of the study to health professionals and service users.

The researcher was sensitive to the fact that both managers (gate keepers) and other health professionals were seriously burdened with the volume of their work and with the complexity of the needs of their patients. The researcher was able to reciprocate the help given by the health professionals by providing workshops to keep the clinic staff informed of the research progress. This collaboration was found to be valuable, particularly in outlining the recruitment strategy of theoretical sampling to staff. It also assisted in recruiting theoretically significant participants (see Section 4.5.7).

While access to host sites was straightforward, participant recruitment proved challenging. According to Anderson & Hatton (2000) this is a normal occurrence when accessing vulnerable groups. They state that: "These studies are both complex and time consuming and do not produce quick research products" (Anderson & Hatton 2000:251).

Homeless people are highly mobile (Bottomley 2001) and some participants did not turn up for interviews. Both the researcher and health professionals could not predict who would actually attend, even when appointment times were organised to fit the schedule of participants. This problem was part of the field experience, and the researcher was psychologically prepared. In the UK, Williams & Allen's (1989) study of homeless service users found similar issues of poor attendance for their

interviews. Similarly, Hall *et al's* (2000) UK study found several homeless participants who having initially agreed to take part did not attend their interviews.

4.4.2 Sample Selection

4.4.2.1 Participant Selection Criteria

As homeless people are not a homogeneous group, and as described in Chapter Two differ in their geographical and social characteristics, the principle of equity was of great importance to the study and was reinforced during recruitment. Elements of the Department of Health policy on Equity and Human Rights (Department of Health 1998) were reviewed and taken into consideration. To avoid discrimination against individuals, and to encompass the heterogeneity of homeless people, a broad definition of homelessness was applied to the study.

The defined sample population included:

> People who are either literally roofless or who live in insecure, overcrowded, dangerous, illegal or temporary accommodation (e.g. bed & breakfast hostels, women's refuges, hostels, friends/relatives floors and squats (Lewis *et al* 2003, McMurray-Avila *et al* 1998).

As stated in the section on support and safety (4.3.3), due to the health risks posed by this sample population, the researcher's defined sample included those individuals with *"non-infectious, non MDR-TB"*. This denoted two weeks or more of TB treatment to ensure that the participant was non-infectious. The sample population included all forms of TB apart from individuals that had infectious pulmonary TB. Table 2 and 3 below outline the inclusion and exclusion criteria and justification.

Table 2: Participant Inclusion Criteria and Justification

No	Inclusion criteria	Justification
1	Over the age of 18 years	The adult age to be able to give informed consent.
2	Homeless – as per definition on previous page	The core research focus of the research is about homeless people with TB. High incidence of TB among homeless people. Limited body of knowledge on this population. Hard to reach and socially excluded group. Inclusion will promote empowerment, through developing a homeless level perspective, giving them a voice and power to influence service provision Contributes to implementing evidence-based practice.
3	Diagnosed with tuberculosis	
4	On tuberculosis treatment for more then two weeks	For participants with pulmonary TB, once on treatment it takes two weeks for them to be non-infectious, and therefore no risks to the researcher of infection.
5	Patients receiving care and support from the host clinic	Support is already in place. Participants are able to receive help if sensitive issues are uncovered by the interview.
6	Living in London	Highest numbers of homeless people with TB in this region of the country.
7	English speaking	Able to provide informed consent. Ease of understanding questions and answers.
8	Willing to share their experiences and perspectives	Volunteering and able to provide informed consent.

Table 3: Participant Exclusion Criteria

No	Exclusion criteria	Justification
1	Under the age of 18 years old	Unable to provide informed consent
2	Diagnosed with multi-drug resistant (MDR-TB) tuberculosis	Presenting risk of exposure of MDR-TB (a serious strain of TB) to researcher, exclusion based on safety issue.
3	Any infectious tuberculosis patients	Risk to researcher, exclusion based on safety issue.
4	With severe mental illness	Unable to provide informed consent.
5	With learning disabilities	Unable to provide informed consent.

4.4.2.2 Sample composition

The final sample consisted of 16 interviews. The sample composed both sexes over the age of 18, who were homeless, had been diagnosed with TB and consented to take part in the study. Collectively, there were ten male and six female participants between the ages of 22-57, with a mean age of 39. There was no restriction on participants according to ethnicity, so the number of participants from various ethnic groups merely reflected the composition of homeless people at the host sites. However, a limitation was that participants needed to be English speaking, as the researcher was, unfortunately, restricted financially in her ability to employ translators. There were ten UK born and six non-UK born participants within the sample population, of which five were asylum seekers/refugees (See Table 4).

Three London based TB/chest clinics were selected as host sites for participant recruitment. The three centres were chosen because they provided the largest potential pool of participants. In selecting three clinics instead of one, participants reflected a broad range of factors including demography, locality and social factors. The first clinic recruited seven participants, the second five and the third recruited four participants. Participants varied in their stage of TB treatment, some individuals had just started treatment, others were in the middle of their treatment regimes and some were near completion. Out of the 16 individuals: 6 had drug resistance

(Isoniazid); 13 were on DOT; and ten were receiving incentives (monetary or vouchers) from their clinics.

Participants were diverse in their type of homelessness. During, the interview phase of fieldwork, there were two rough sleepers, two sofa surfers, seven hostel users, four individuals in temporary accommodation and one individual squatting. Ten out of the sixteen individuals had a previous history of sleeping rough. Substance use was common among the participants, with 12 out of the 16 having used substances at sometime. Four individuals have not used substances, at the time of fieldwork, seven participants were currently using some form of substance, while five participants had previously used substances but were not currently. Five out of the 12 participants mentioned above were on methadone treatment for previous heroin use. There were three known commercial sex workers (three females), two who were still working. There were two participants diagnosed with HIV (both female) of which one was a commercial sex worker (confirmed by the hospital HIV/TB team) (See Table 4 below).

Table 4: Participant Summary

Host Site Composition	**Housing Status**
Clinic A: 7 Clinic B: 4 Clinic C: 5	Currently: Rough sleeper= 2, Sofa Surfer=2, Hostel=7, Temporary Accommodation=4, Squatting=1 Previous history of rough sleeping: 10 (2 currently)
Demographics	**Substance Issues**
Female: 6 Male: 10 Age: 22-57, mean 39 UK Born 10; Non-UK born 6. Asylum seekers/ Refugees: 5	Substance use: Crack Cocaine, Heroin-injecting, Heroin-smoking (Brown), Marijuana & Alcohol No substance use: 4 Currently substance user: 7 Previous substance user: 5 Methadone use: 5
CSW	**Tuberculosis Status**
Known commercial sex workers: 3 (2 previous, 1 current) HIV: 2	Drug resistance: 6 Isoniazid resistant DOT: 13 (3 non DOT) Incentives: 10

4.4.2.3 Sample size

Although the sample size of 16 participants was relatively small, the data collected was rich. According to Baum (2002), Rubinstein (1994) and Patton (1990), qualitative research, often has small samples. Furthermore, Holloway & Wheeler (1996) maintain that there is no justification for a large sample size in qualitative research, as the aim was to provide richness of data rather then randomisation for verification or generalisation purposes (Ezzy 2002). Furthermore, various scholars acknowledge that 12-20 participants are normally adequate for a qualitative study (Baum 2002, Rubinstein 1994). Additionally, the final sample size enabled the saturation of the categories and their properties, thus the most important areas were adequately investigated (Ezzy 2002, Patton 2002).

The sample size is consistent with Grounded Theory's procedure of theoretical sampling and saturation (Tuckett 2004). The theoretical sampling procedure guided the entire recruitment process, and determined the point at which recruitment stopped (Tuckett 2004). The process was controlled by the emerging theory, through simultaneously collecting, coding, and analysing data to establish what data to collect next (see Sections 4.4.2 and 4.5.7).

4.4.3 The Interview Process

4.4.3.1 Conducting Interviews

Initial questioning was of an open-ended nature (Harvey-Jordan & Long 2001). As recommended by Glaser (1998) interviews were conducted with little forcing and structure. The researcher conducted semi-structured interviews consisting of open-ended questions that defined the area to be explored, and from which the researcher could diverge to pursue an emerging theme or concept (Britten 1995). In interviewing, the researcher aimed to discover the participant's own framework of meanings and the researcher avoided forcing her preconceptions through predetermined questions (Britten 1995). Dearnley (2005) supports the use of the semi-structured approach to encourage depth and allowing concepts to emerge. An interview schedule was used, not so much to direct questioning, but merely as a guide in the interview process. The interview schedule was dynamic and was altered

during each interview, reflecting new ideas and themes that had emerged from previous interviews, to enable the researcher to keep in mind the theoretical components that had been previously discovered (Britten 1995).

Throughout the interview process, the researcher remained open to emerging concepts. According to Cryer (2000) keeping an open mind should be fundamental to all research.

> [it is] particularly important when talking to others; without it, one is liable to hear (take in) only what one already knows (Cryer 2000:203).

Glaser (1998) states that such openness enables constructions to emerge that may be different to those expected at the outset. Since it was not known what participants would consider important issues, there was little direction (forcing) offered by the researcher (Britten 1995).

Once the researcher had introduced herself and made the participant feel comfortable, the participant began by telling the researcher about their current circumstances and their experiences that led them to where they are now. This gave participants a point on which to commence, but allowed them flexibility to direct the interview. Throughout the interview, the researcher asked for clarification, and where necessary checked participant's meanings - rather than relying on her own assumptions (Britten 1995). For instance, some of the participants used 'street' jargon; and one, in particular, used the term: "sharing the bottle", which the researcher did not initially recognise. This meant sharing the crack cocaine pipe. Through clarification, the researcher increased her field vocabulary and thus improved the understanding of the meanings of participants in subsequent interviews. Furthermore, to prevent misunderstanding and to increase rapport, the researcher used participants' own terminology and vocabulary as much as possible (Britten 1995).

Subsequent interviews incorporated issues that had been raised by previous participants (Glaser & Strauss 1967). Attention was paid to ensuring that questions

were not leading and that probing was limited when topics were found to be difficult for participants, as recognised through observation of verbal and non-verbal signs (Oka & Shaw 2000).

According to Nunkoosing (2005), power is always present in the transactions of interview, as it is in all human interactions. The power of the researcher rests in her influence as a seeker of knowledge (Nunkoosing 2005). There are significant issues in interviewing when working within an interpretive paradigm, seeking in-depth, subjective knowledge. The need for reciprocity was exacerbated by an unequal relationship between the researcher and the vulnerable study population. The question of reciprocity was therefore important to address in this qualitative study (Oka & Shaw 2000). The researcher was always conscious that participants voluntarily 'opened up' their experiences, giving their time, sharing intimate stories and unique insight. Within the emotionally intensive interview situation, some participants questioned the researcher's interest in the subject. The researcher did not want to impose her own notions on the interview, but if questions were not answered, the researcher was aware that participants' willingness to respond could be affected (Britten 1995). According to the National Health Medical Research Council (2006:1) "….good qualitative research requires the establishment of rapport between the researcher and the participant". Therefore, in order to develop rapport and trust, the researcher felt the need to reciprocate and disclose personal information about her interest in the research subject (see Appendix A). The researcher provided just enough information to attain trust and openness in the interaction.

The reciprocal nature promoted by the researcher in the interview situation encouraged the interviews to revolve around the concerns and interests of research participants, rather than that of the researcher (Glaser 1998). Interviews were carried out as conversations in which the participants focused on subjects they wanted to discuss. There were a number of advantages in applying this flexible approach. In particular, participants could take ownership of the interaction, and a more equal exchange of knowledge could be maintained. Participants appeared to be comfortable and confident with the interview situation, which enhanced the quality of the data

collected. This shift of emphasis from researcher to that of participant's concerns is argued to produce more meaningful knowledge (Glaser 1998).

As mentioned earlier, questioning evolved and developed through feedback from participants. At the outset, for instance, one of the questions posed by the researcher was, 'describe a typical day'. This question appeared valid and broad enough to elicit an in-depth explanation. However, it became clear from early participant feedback that there was no such thing as a 'typical day' in the lives of the homeless. This vital feedback enabled the researcher to improve the questioning by simply revising it to "tell me about your day". Thus the researcher found that altering the question to suit participants, as advised in Grounded Theory, enhanced the quality of interviewing. Furthermore, Rubin and Rubin (1995) state that adjusting the design as the researcher goes along is a normal, expected part of the qualitative research process.

External disturbances were minimised in the interview room. All the interviews were carried out as individual face-to-face interviews with the researcher, at a time and date that was convenient for participants. Additionally, the researcher coordinated times and dates with managers to limit disturbance to the working environment, as she was conscious that she was using hospital facilities.

4.4.3.2 Duration of interviews

The duration of interviews is an important consideration and it is clear in the literature that there are conflicting views about the appropriate length of interviews (McCann & Clark 2005). Field & Morse (1985) encourage the use of short interviews, while Seidman (1998) and Douglas (1985) argue that interviews should be lengthy, possibly around 90 minutes in duration.

The reality of the field experience was that homeless participants had a range of issues, such as illnesses and drug addiction that impacted their stamina, memory and concentration. In these situations, Kellehear (1996) advocates that interviews are

kept short. Therefore, the majority of interviews lasted between forty-five and sixty minutes. One interview lasted twenty minutes, as described below.

Holloway & Wheeler (1996) suggest that the participants themselves should determine the duration of interviews. At the start of interviews it was made clear that interviews could be stopped at any time. If participants appeared upset by the discussions, the researcher asked them if they wanted a break or to stop the interview. All participants wanted to carry on and speak, apart from one participant who wanted to leave the interview early (20 minutes). Although this particular participant was not distressed by the interview experience, the researcher was concerned for the participant's safety. During the interview, the participant's partner, who was in the waiting area of the clinic, became impatient. He began to get agitated, and argumentative, knocking at the door, and telephoning the participant on her mobile phone. Although, at no time, did the researcher feel unsafe or threatened in the interview situation, the interview was completed early so as not to contribute to the tension between the participant and her partner and to prevent the risk of harm to the participant.

According to Britten (1995:252) "it is possible to collect data even in stressful circumstances". Other studies conducted with vulnerable groups reveal that the duration of their interviews was equally short (Finkelstein 2000 [25-30 minutes] Myers 2000 [25 minutes to one hour and 50 minutes]). From the example given from the researcher's field experience, despite the short duration of the interview, the data gained was important.

Williams & Allen's (1989) acknowledge the difficulties in data collection and in their study of the homeless, experienced problems in interviewing participants. Problems were encountered in the interview situation. For instance, some participants needed their prescribed methadone for heroin addiction, and were concerned to complete interviews in time to receive it. At all times, the researcher considered ethical issues of informed consent and only interviewed people who were 'sober' and not intoxicated.

4.4.3.3 Eliciting Rich Data

Whereas Shanks (1981) found barriers in eliciting sensitive information among their homeless participants, the researcher did not experience this problem, as data was always rich, even if some interviews were short. The researcher discovered that the content was rich in its openness about situations such as the drug scene, violence, commercial sex work and other highly sensitive topics that frequently emerged. As described in Chapter Four, in Grounded Theory 'all is data', thus both the interview experience and outcomes were documented as data in field notes. Such information produced more variables to code and analysis (Glaser 1998). In applying the concept of reflectivity outlined in Chapter Four, the researcher's own reflections were documented.

According to Weiss (1994), if researchers have good listening skills they can provide participants with a chance to release their emotions, with rapport between the researcher and the participants contributing to the richness of data. The researcher used active listening skills such as an open posture, affirming what the participants said by nodding and offering approving remarks. Although many of the participants found the interview process emotionally intensive, they also found the experience 'therapeutic'. Some mentioned after the interview that they were glad someone was listening to them. To illustrate this, one participant stated that "I've never chattered for so long in my life [laugh]. I can't chat to my psychologist that long [laugh]" (P12: page 24). Participants were at times exposing their vulnerability, which was why the researcher tried to make them feel as comfortable during interviews as possible. Qualitative interviewing provided the researcher with opportunities to involve the participants emotionally about sensitive topics (Lee & Renzetti 1993). Padgett (1998:37) states:

> Many qualitative interviews elicit intense discussions of painful life events such as divorce, death of a family member, and domestic abuse. Sensitivity to research ethics dictates that we do not introduce these topics gratuitously; they should either be volunteered by the respondents or inquired about when they are the focus of the study.

There are similarities between the research interview and therapeutic interviewing. The research interviewer is similar to a therapist who encourages the individual to develop thoughts and memories, by eliciting the individual's emotions, and by listening intensely to them (Weiss 1994). This 'therapeutic' nature of qualitative interviews at times raised the ethical dilemma of roles that might be adopted by the researcher (researcher-health professional) (Patton 1990). For example, a couple of the participants appeared to regard the researcher as an advocate, nurse or 'therapist'. One individual queried information about his treatment and how he could encourage a friend to come to the clinic. Nonetheless, the advantage of conducting the interviews at TB clinics was that participants had support already in place to address such needs.

The researcher did not take on a therapeutic role (nurse), and clarified that her position was that of a researcher and that such issues could be addressed by the participant's health professionals. The researcher encouraged an open dialogue and relaxed atmosphere, but at all times was clear that she was conducting a research interview and not a therapeutic one (Weiss 1994, Patton 1990).

According to Lee (1993), there is significant value in conducting a single interview, particularly in providing participants with a sense of freedom to openly discuss subjects and issues, knowing that they would not meet the researcher in such a situation again. However, the single interview has the disadvantage of being detached. In some instances, follow-up interviews would have been beneficial in following a participant's progress. Nevertheless, in considering the mobile condition of homeless people, and the problems in recruiting such participants, the single interview was not only preferable, but also deemed the only one feasible.

4.4.3.4 Audio-Taping & Transcribing Interviews

The researcher used an audio tape recorder to document interview data, and all participants consented. Taping and transcribing interviews is common in qualitative research, and although a number of Grounded Theorists have audio-taped and transcribed (Lee 1993, Kearney *et al* 1995) according to Glaser (1998) this can be a

waste of time in Grounded Theory - which moves fast in generating concepts that fit with data (Glaser 1998). The researcher found this to be the case, and furthermore, found transcribing immensely time consuming, as each hour's worth of interview often took between seven to sixteen hours to transcribe, depending on the quality of the tape, and the tone of voice and accent of the participant. Thus, in any future studies using Grounded Theory, the researcher would not use audio recording and transcribe interviews. In addition, McCann & Clark (2005) suggest that audio recording of interviews can cause stress to participants, because they fear that the information may be used against them.

As a PhD student, the researcher was required to record and transcribe under university guidelines in order to provide evidence of research for thesis purposes. McCann & Clark (2005:15) argue that the "use of audio recorder does not completely remove the need for taking notes". Dick (2005) suggests that researchers take key-word notes during the interviews and convert them to themes afterwards. This would have formed a distraction during the interview, thus the researcher documented observations and emerging concepts immediately after the recording had stopped and the participant had left. Subsequently, recordings were listened to twice, and transcripts read between 4-6 times (for coding purposes). Interviews were transcribed verbatim, and all identifying references were removed to ensure anonymity. The researcher later analysed the transcribed interviews with supervisors to see whether any leading question had unduly influenced the response of the participant. This process enabled subsequent interviews to improve.

4.4.3.5 Field Notes

As explained above, the researcher made field notes in addition to transcripts. Field notes were hand written on the same day as the interview to recall as much information as possible**.** The field notes contained information on the environmental setting, the communication between her and the participant and the researcher's assessment of the interview experience, such as the quality of the interaction and any problems that arose. The researcher learned a lot by observing body language, noting down such things as the ambience, feelings and other pertinent interpretations of the

research context. One of the values of the field notes was that it enabled the researcher to document thoughts and feelings about the interviews, which would not have come across in the recordings, and allowed the researcher to adhere to the requirements of reflectivity in order to acknowledge bias.

4.5 Data Analysis

As the researcher entered the 'field', she acknowledged that the research problem was to be discovered from the homeless people themselves. The initial research question was broad and did not include a hypothesis to test or verify. Because the researcher had a pre-research assumption that was TB as a subject of concern, this was handled according to the Grounded Theory method, whereby she noted this in memos that were constantly compared. The researcher's preconceived assumption was quickly abandoned, as it differed significantly to what was emerging.

Glaser (1998) acknowledges the difficulty in providing a simple explanation of the Grounded Theory method, where the process "happens sequentially, subsequently, simultaneously, serendipitously and scheduled" (Glaser 1998:1).

To provide structure to this thesis, the researcher has broken down the various processes involved in conducting this Grounded Theory study. However, it is important to note that what actually occurred was a systematic process that involved a number of interrelated steps in data collection and analysis (interviews, field notes). Grounded Theory provided a total package for data collection and analysis (Glaser 1998). As described in Section 3.4.2, Grounded Theory is multivariate, and involves an intensive process of "…collecting, coding, analysing, memoing, sorting and writing" (Glaser 1998:15). As the data collection and coding advanced, the codes and the memos accumulated. The process of sorting occurred after all the categories were saturated. Underpinning the process, was the need for the researcher to let go of preconceived ideas related to the research problem, and listen carefully to the main concerns of research participants. Over time, the methodological phases within Grounded Theory began to produce clear results.

The researcher selected the main methodological texts to guide the research process. This was important to establish that the Grounded Theory procedures followed as closely as possible to the classic 'Glaserian' approach. The main texts were:

- 'The Discovery of Grounded Theory: Strategies for Qualitative Research' (Glaser & Strauss 1967);
- 'Theoretical Sensitivity: Advances in the Methodology of Grounded Theory' (Glaser 1978);
- 'Basics of Grounded Theory' (Glaser 1992); and
- 'Doing Grounded Theory: Issues and Discussions' (Glaser 1998).

The Grounded Theory method determined the approach used to analyse the results. All data were systematically coded and the technique of constant comparison was employed in order to build on and refine theoretically significant categories. The categories obtained from the data were constantly compared with previously reviewed data (transcribed interviews & field notes) so that similarities and variations could be identified and extracted. The simultaneous process of coding and analysing elevated the data from a descriptive or empirical level to a conceptual level, which Glaser describes as creative (Glaser 1978, 1998).

During data collection, the study's approach became progressively more centred, concentrating on the emerging theory. The Grounded Theory approach in data analysis halted when data saturation was reached – the point at which additional data collection did not generate any new information (see Section 4.5.8). The outcome of the Grounded Theory study was a theoretical model that explained the homeless/TB phenomenon from the perspectives of participants. The researcher termed this theory 'Survivalising' (see Chapter Five).

4.5.1 Theoretical Sensitivity

Glaser (1978, 1992) describes theoretical sensitivity as the researcher's capacity to generate concepts from data. This engenders a number of aspects that include the

researcher's understanding, awareness and aptitude. These factors promote the creation of categories (and their properties) and assist the researcher in connecting these categories and assimilating them into a theory - in line with the emergent codes (Glaser 1992:27). In highlighting the importance of having theoretical sensitivity, Glaser states that:

> A researcher may be sensitive to his personal experience, his area in general and his data specifically, but if he does not have theoretical sensitivity, he will not end up with Grounded Theory.

Furthermore, Glaser (1978:2) acknowledges that as human beings, researchers bring their social psychology to research; he states that it is the: "…conceptual build-up that makes him [researcher] quite wise about the data". He recommends that:

> …the researcher should be sufficiently theoretically sensitive – by training - so he has the tools within him to self-consciously conceptualise and formulate theory as it emerges from the data (Glaser 1978:44).

Therefore, it was important that the researcher not only received broad research training, but also acquired field experience. The researcher gained training as part of the PhD student program at Bucks New University, and through work as a project co-ordinator (see Chapter Two and Appendix B). Nursing experience, both academically and clinically, was particularly relevant in enhancing the researcher's theoretical sensitivity. This experience provided opportunities to witness clear examples of coherent theory and practice, which aided her in generating a beneficial and practical theory.

Early on, the researcher was acutely aware of the need to follow Grounded Theory procedures properly and accurately, and although she had carefully read the Grounded Theory books of Glaser (1978, 1992, 1998, Glaser & Strauss 1967), she felt the need to develop conceptually. Therefore, theoretical training was undertaken in 2004 (New York City), 2005 (New York City) and 2006 (San Francisco) with the Grounded Theory Institute. The first two workshops helped the researcher to

understand the Grounded Theory techniques and technical language of the methodology, while the third workshop was crucial in assisting the researcher in conceptualising. One of the key skills the researcher learned was to distinguish between the research methods of other qualitative studies and those of Grounded Theory, learning to avoid description or 'story talking' but to talk conceptually.

The introduction of the concept of theoretical sensitivity required the researcher to conceptualise, make abstract connections, and think in a "multivariate" manner (Glaser 1978:3). An important aspect of enhancing theoretical sensitivity was to enter interviews with as few predetermined ideas as possible and to acknowledge that the research problem would be discovered through the Grounded Theory process (Glaser 1978).

4.5.2 Data Management

In the last 15 years, there has been an upsurge in computer software packages designed to facilitate qualitative research (Morison & Moir 1998). Nonetheless, as advised by Glaser (1998) the researcher did not use computer software to aid analysis or retrieval of data. The decision was influenced by a number of factors, but two in particular arise from the cautionary advice of Glaser (1998) and the researcher's preferred approach.

First, in attempting to follow as closely as possible the classic Grounded Theory approach, the researcher took on advisement Glaser's (1998:185-6) warning against the 'technological traps' of data analysis tools such as NUDIST. According to Glaser (1998), they create restrictions that inhibit the researcher's development of skills and impose time-consuming learning curves. Although Morison & Moir (1998) highlight the benefits of NUDIST facilitated analysis for such things as data retrieval, data management, and coding, they are in agreement with Glaser (1998) in outlining the limitations of such programs, as computer software can fundamentally alter the nature of the analytical process in unpredictable and undesirable ways.

Second, the researcher felt that using computer software could form an obstruction, distancing her from the data, which would not allow the creative elements of Grounded Theory to arise. In agreement, Glaser (1998) considers that computing technology appears to be an option, but forms a hindrance rather than an aid to creativity. The researcher discovered that Grounded Theory was not only a systematic method, but also involved a creative process. The researcher agrees that the use of computer software's automatic coding hinders the discovery of theory in the data, which requires a level of conceptual and creative thinking that computer programs cannot offer.

The researcher managed all data by hand. However, she stored a backup copy of the transcribed interviews, coded interview data, field notes, coded field notes, memos and lists of emergent codes on her computer. As described earlier, interviews were transcribed verbatim, memos were written by hand or typed up on a word processor, and filed in a 'memo bank' (Word document) in order to organise data. The researcher also stored this data in a hard-backed notebook. For ethical reasons of confidentiality, no distinguishing details of participants were present on such data. An Excel-spreadsheet was used to provide an audit trail, which consisted of several categories linking the concepts and coding to the raw data (see Section 4.7). This provided a valuable reference tool, for possible evaluation, and demonstrate the groundedness of the theory to the data.

4.5.3 Coding

According to Glaser (1978), the fundamental affiliation between data and theory is a conceptual code. The code theorises the relationship of collective empirical indicators contained in the data. In this manner - by developing theory through theoretical connections between conceptual codes (categories and their properties) (Glaser 1992) - the researcher discovered the Grounded Theory of Survivalising mentioned above. By coding, the researcher fractured the data and then grouped the codes conceptually to explain the experiences of homeless participants and what they were doing to resolve their concerns and to make their lives viable. The researcher

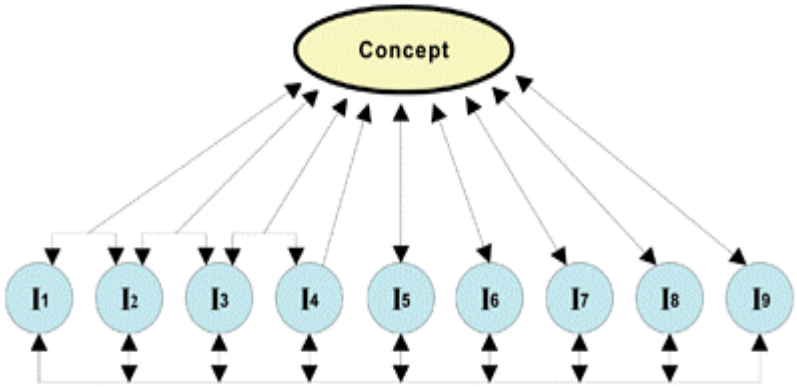
worked in conceptualising data by constant comparison of incident with incident, and incident with concept, to discover categories and their properties (Glaser 1992).

In this study, the researcher used two types of coding: substantive and theoretical (Glaser 1978, 1992, 1998). This first encompassed open coding, and later selective coding. Substantive coding conceptualised the substantive data, while theoretical coding conceptualised how the substantive codes related to each other as concepts that were then integrated into the theory. Substantive and theoretical coding occurred simultaneously and triggered memoing (see Section 4.5.9). However, in discovering codes in the data, the centre of attention was placed upon substantive codes. Greater attention was placed on theoretical coding within the sorting stage and the amalgamation of memos (Glaser 1978).

Codes in Grounded Theory are generated through the concept indicator model, and it is following this framework for generating codes that theory emerges from the data, and thus is grounded.

To illustrate this process, Glaser (1978:62) provides a diagram of the Concept Indicator Model shown below in figure 3:

Figure 3: The Concept Indicator Model



Grounded Theory is founded upon the concept-indicator model of constant comparisons (see Section 4.5.8) of incidents (indicators) to incidents. As shown in the above model, any number of indicators can be constantly compared to provide the concept. When a conceptual code is generated, incidents are compared to the emerging concept (Glaser 1978).

According to Glaser (1978:62), this forces the researcher to find:

> …consistency of meaning between incidents (indicators), which results in a coded category and its properties…From the comparisons of further incidents (indicators) to the conceptual codes, the code is sharpened to achieve its best fit while further properties are generated until the code is verified and saturated.

Thus, concepts and their dimensions have to earn their way into the theory by systematic generation of data. The interchangeability through constant comparison produces saturation of concepts and their properties (Glaser 1978).

The coding process served as a basis for further analysis aiming to develop a conceptual model for identifying the specific links between social processes (Ratcliff 2002, Robson 2002). The analytical techniques of open coding, theoretical coding and selective coding, which arise from discovery of the core category, are described below.

4.5.4 Open Coding

Data from transcribed interviews and field notes were conceptualised line by line. In the outset of the study everything was coded in order to discover the participants' main concerns and how they were being resolved. Line by line coding ensured that the researcher verified and saturated categories, minimising the risk of omitting important categories and ensuring their grounding in the data. The result provided a rich, dense theory and corrected the forcing of forced themes and ideas. The researcher did all her own coding by hand, with no assistance from computer soft ware, as mentioned earlier.

Coding was done in the margins of the transcripts and field notes. This phase was tedious, as the incidents in the data produced many concepts, which needed to be constantly compared with previous ones. As more data was coded, new concepts emerged, which were eventually renamed and ultimately modified the theory.

As was stated in the research design section (see Section 4.2) it was important that the researcher had no concepts or 'pet' theories.[13] She had the directive to generate from the data an emergent group of categories and their properties that fit, worked and were relevant and modifiable for the integration into the theory (Glaser 1978, 1998). In compliance, the researcher began with the first interview data, which involved coding for all incidences into categories and their properties in the substantive area of homelessness. Glaser describes this as "running the data open" (Glaser 1978:56).

Open coding set the initial stage of constant comparative analysis (see Section 4.5.8), and enabled the researcher to verify and saturate categories and reduced the risk of overlooking an important category (Glaser 1978). Coding triggered theoretical propositions, leading the researcher to disrupt coding to write memos (see Section 4.5.9).

Through open coding, the researcher discovered new areas of enquiry. This guided subsequent data collection activity, determining the direction of theoretical sampling, and establishing the relevance of what was emerging. In Glaser's (1978) narrative of the psychological experience of open coding and those who experience it, he states that:

> …the analyst is most tested as to his trust in himself, in the Grounded Theory method and his skill to use the method and as to his ability to generate codes and find relevance (Glaser 1978:57).

[13] Although the researcher initially felt that TB was a main concern, the process of constant comparison addressed this issue of bias (see Section 4.6).

Early on, the researcher experienced an emotional burden in conducting open coding, fearing that little, if anything, would emerge. The contrary proved true, as the constant comparative method facilitated the generation of codes. Open coding generated 195 codes in this study.

The process of open coding was important in developing relevant conceptual ideas. This part of the Grounded Theory process was inductive, as concepts that emerged were "rooted in data" (Glaser 1998:38) rather then from preconceived grand theories or other sources of literature. To discover the properties of concepts through analysis, the researcher asked three pertinent questions (Glaser 1998:57):

- What is the data a study about?
- What category does this incident indicate?
- What is actually happening in the data?

In thinking about these questions, the researcher was kept theoretically sensitive and provided a transcendent approach in analysing, collecting and coding the data. The process enabled the researcher to focus on patterns among incidents that generated codes, while coding into as many categories as possible. Open coding allowed new categories to emerge and new incidents to fit existing categories. This elevated the emerging theory conceptually beyond description of incidents to an abstract level (Glaser 1998).

4.5.5 Core Category

Through open coding, the researcher was able to "generate an emergent set of categories and their properties" (Glaser 1978:56) that in theory "accounts for the patterns of behaviour which was relevant and problematic for those involved" (Glaser 1978:93). As the researcher proceeded to compare incident to incident in the data, and incidents to categories, a core category began to emerge which was able to explain the main concern of participants.

In this study, as mentioned earlier, the researcher found the core category as Survivalising, a basic social process that engaged homeless people in a series of activities (processes) aimed at resolving the adversity of their life.

It was clear during the first few interviews that Survivalising was the main concern of participants, and thus the core category in the homeless-TB experience. Nevertheless, as Glaser (1998) suggests, it would have been risky to select a core category too early in the data collection stage. The researcher did not want to bias the study by stating a core category so early on; so for verification continued to interview participants. By the seventh interview, it had become clear that this category had emerged as core. It was linked to the four other categories that emerged as 'Zoning-out, Bottoming-out, Self-realisation and Healing'.

The criteria for establishing the core variable within a Grounded Theory, according to Glaser (1978:95-96), were met when the following requirements for a core variable were fulfilled:

- It must be central, in that it is related to as many other categories (and their properties) as possible.
- It must recur frequently in the data. By its frequent recurrence, it comes to be seen as a stable pattern and becomes more and more related to other variables.
- It relates meaningfully and easily with other categories.
- It has clear and 'grabbing' implications for formal theory.
- It is completely variable. Its frequent relations to other categories make it a highly dependent variable in degree, dimension and type.
- It is readily modifiable and adaptable to different conditions and substantive areas.

The core category was the pivotal point for the theory; all the categories related to it, and it accounted for most of the variation in the patterns and behaviour of the

participants. Once the theory of Survivalising emerged (see Chapter Five), and was clearly connected to the categories and grounded in the data, Survivalising was properly adopted as the core category.

4.5.6 Selective Coding

Selective coding was carried out once the core variable was discovered. At this stage, the researcher continued to rigorously write memos (see Section 4.5.9). The identification of the core category enabled the researcher to stop open coding, and selectively code data with the core guiding the selective coding procedure. This process enabled the researcher to focus on the core category and ignore other concepts that had little importance to the core and its subcores. The researcher then selectively sampled new data with the core as the focus. This involved the process of theoretical sampling, which became the deductive element of Grounded Theory. Selective coding delimited (see Section 4.5.5) the study and was carried out by going over interview transcripts, field notes and memos that were already coded while continuing to code newly gathered data. As the study progressed, the researcher found that coding rapidly become more efficient, as she concentrated on the core category, other connected categories, and their properties. The researcher recorded connections between categories in memos and continued doing this, adding to the sample as necessary, until she achieved theoretical saturation (see Section 4.5.7).

4.5.7 Theoretical Coding

Theoretical coding involved managing the conceptual codes originating from open coding, theoretical memos, and the sorting process, which produced the connections between the data and the findings (Glaser 1998). In the course of open coding, the data were broken up, coded and analysed. Theoretical coding involved relating the substantive codes to theoretical codes. This formed the deductive stage of the Grounded Theory process.

In illustrating the use of theoretical coding, Glaser (1978:72) states that "the fractured story is weaved back together again". Because the theoretical codes shaped

the theoretical findings, it was vital that they were emerging from the data and not externally (Glaser 1998). As the researcher had no 'pet' theories, she could maintain a sense of openness and merely needed to learn the 18 coding families, exemplified in the book "Theoretical Sensitivity" (Glaser 1978), as well as the additional codes which were later described in "Doing Grounded Theory" (Glaser 1998). These were typed up as a framework that was used throughout the coding process (Glaser 1978, Glaser 1998) (see Appendix G).

The researcher analysed how and why categories and properties were occurring and were related to one another. When the researcher felt she had discovered the emergent theory (core category), it was verified through theoretical sampling by asking participants relevant questions. It became apparent that what the researcher was getting from the data was what the participants were experiencing as their main concern and how they were dealing with it to survive under adverse conditions.

4.5.8 Theoretical Sampling & Theoretical Saturation

Theoretical sampling is related to Grounded Theory (Higginbottom 2004) and was used by the researcher as a data collection process for developing the theory. The procedure allowed her to establish emergent themes and to continuously seek appropriate data. As categories (concepts) emerged from the data, the researcher added to the sample to increase and strengthen the emerging theory (by defining the properties of the categories) and to understand the relationship of categories.

The theoretical sampling procedure dictated the choice of participants (Glaser & Strauss 1967), and thus, the researcher recruited participants who were able to provide insight into the emerging aspects of the research. The overall process of selection emerged based on the concepts that developed from the data (Glaser & Strauss 1967).

In selecting the most knowledgeable participants, the researcher was able to increase the quality of the data gathered in each interview. According to Morse (2000:4):

> There is an inverse relationship between the amount of usable data obtained from each participant and the number of participants.

In other words, the greater the amount of usable data a researcher is able to gather from a single participant, the fewer participants will be required. According to Glaser & Strauss (1967), there is no set number for a sample size in interviews for theoretical saturation to occur. The key was to generate enough in-depth data to allow for the emergence of theory (Glaser & Strauss 1967). It was therefore essential to obtain a large enough sample size to generate sufficient data (Auberbach & Silverstein 2003).

Eventually, the researcher reached a point of diminishing returns with category data collection and analysis. Subsequent interviews added nothing to what the researcher already knew about a category, its properties, and its relationship to the core category (see Section 4.5.4). When this occurred, the researcher stopped coding for that category. The researcher then moved to the next category until that too was saturated. The researcher continued expanding the sample size until interview 16, when no new data was revealed, and what was emerging became repetitive (Douglas 2003, Goulding 2002, Locke 2001). At this point, the researcher had reached theoretical saturation (Higginbottom 2004).

Participants in the current study engaged in the process of Survivalising, as evident in the data. The degree to which individuals were, for example zoning or healing, reflected the variabilities of their experiences and is manifest in the complex and dense theory of Survivalising. Glaser (2004:7) claims that "In Grounded Theory, seeking negative cases is not a procedure". The researcher's focus was to search for comparative incidents by theoretical sampling and to discover incidents that were similar (or different) and thus build upon the theory, in essence seeking conceptual saturation (Glaser 2004).

In the process of theoretical sampling, two participants interviewed were not included in the results chapter, as their experiences were contextually different from the 14 others, and their inclusion did not build upon the theory of Survivalising. In effect, these two individuals' main concern was still Survivalising, but the process was dissimilar from the 14 others - being primarily related to a desire for asylum in the UK. Gaining identity papers and legal documents was seen as their means for survival. The process of constant comparison and conceptual saturation confirmed that their data fit the theory of Survivalising, but made a limited additional contribution to the theory as a whole (Glaser 2004).

4.5.9 Constant Comparative Method

Much of what has been described earlier involved the constant comparative method. Constant comparison is a methodical process to develop and refine emerging theoretical categories and their properties through systematic coding and analytic procedures (Glaser 2004). It was used in the current study to analyse data and to establish the best fit of concepts into a concise, detailed and integrated theory of the experience of homeless people with TB.

This method was the binding and central process within Grounded Theory. The first stage of the constant comparative method involved the researcher taking the first interview transcript and open coding for every incident (see Section 4.5.3). It entailed asking:

- What is going on here?
- What is the situation?
- How is the person managing that situation?
- What categories are indicated? (Glaser 1978)

The researcher then coded the second interview, staying aware of the information in the first interview, and coded subsequent interviews with the emerging theory in mind. In sum, the constant comparison involved comparing data set to data set

and later comparing data set to theory. During constant comparisons, concepts emerged rapidly, so the researcher frequently had theoretical ideas and immediately noted them as memos (see Section 4.5.9).

Glaser & Strauss (1967:105) illustrate the constant comparative method as a constantly developing process, comprising four stages:

Stage 1: Comparing incidents to category

Stage 2: Integrating the categories and properties

Stage 3: Delimiting the theory

Stage 4: Writing the theory

Stage 1: Comparing Incidents to Category

This stage of the constant comparative method involved "comparing incidents applicable to each category" (Glaser & Strauss 1967:105). As described earlier in the section on open coding, all incidents were coded into as many categories as possible. As more data emerge, codes began to fit existing categories.

For example, the category of zoning-out, which explains the first stage of Survivalising, emerged quickly from comparisons of responses to coping with the adversity of homelessness. All relevant responses involved the participant's way of dealing with managing their situation.

> *"...I was drinking and I took drugs...I use to get some drugs and didn't know where I was so I was always doing...that's the only way I could deal with it...And you have to have a drink to just to get through the day..." (P1)*

> *"I wake up and in the morning I just have a drink to blank everything out. I don't want to think about it. I know it's not right ...I do it to forget..." (P10)*

"...having a drink with the guys...having a good old smoke, having a laugh and that makes me happy...I smoke Rock, I smoke Brown, and I drink a lot lot. And I enjoy drinking a lot...That's my typical day, drinking and smoking...I love it, but I know it's not good for me... I've not stopped for three days" (P2)

The researcher kept a trail of the comparison groups (street, hostel or sofa surfer homeless) in which the coded incidences occurred. The constant comparative process quickly generated theoretical concepts of the properties of the category.

At times, the researcher experienced conflicts in her conceptualisations, for instance, in deliberating between theoretical ideas in focusing on the analysis of the next incident. It is at this stage that Glaser & Strauss (1967) advise that the researcher interrupts coding to write a memo. Thus, throughout the Grounded Theory process, but, in particular with open coding, these theoretical propositions were noted in memos. The concepts that emerged were always grounded in the data and hence were not impressionist or "not speculative" (Glaser & Strauss 1967:107).

Stage 2: Integrating the categories and properties

The second stage of constant comparison was that of integration of categories and the properties. This process involved the switch between comparing incident to incident to that of comparing of incident with properties of the category, the result of the initial comparison of incidents (Glaser 1967). While constantly comparing the incidences, the issue of cycling which was about the individual moving from place to place or sofa to sofa, emerged from the data as one of the properties of zoning-out. Cycling was found to be what confronts the individual in their social world.

I was on the streets for twenty years...miserable, in and out of hostels...(P10)

...You couldn't really plan ahead and everyday was pretty much the same, just a case of strolling on by, doing what you had to do (P6)

Living on the streets was horrible. Really was some rough times, you see some horrible things (P11)

As the theory of Survivalising developed, different categories and their properties became integrated through the process of constant comparisons. This method pushes the researcher to consider the theoretical meanings of each comparison (Glaser & Strauss 1967). As data was collected through the process of theoretical sampling, the integration of the theory was developed by allowing the concepts to simply emerge (see earlier Theoretical Sampling section). The Grounded Theory process of jointly collecting and analysing the data was an integrative strategy (Glaser & Strauss 1967), which allowed theoretical patterns to be discovered and provided depth to the theory.

Stage 3: Delimiting the Theory

The discovery of the core variable of Survivalising enabled the integration of the theory around this core variable, which delimited the theory, and focused the research (Glaser & Strauss 1967). Delimiting occurred at two points (the theory and the categories). The first stage became more concrete, in that significant alterations or changes were less frequent as the researcher compared the next incidents of a category to its properties. Subsequent alterations primarily occur to elucidate the theory, by removing "non-relevant properties, integrating elaborating details of properties into the major outline of interrelated categories and—most important—reduction" (Glaser & Strauss 1967:110). The process of reduction occurred when the researcher discovered the fundamental consistency in the initial set of categories or their properties and then recreated the theory with fewer "higher-level concepts" (Glaser & Strauss 1967:110).

The second point of delimiting the theory was the reduction in the initial set of categories for coding (Glaser & Strauss 1967). As the theory developed, it became reduced to that of the discovered core variable of Survivalising. This enabled the researcher to reduce the initial list of categories for collecting and coding data, in

accordance with the theory. Finally the core variable and only categories that related to Survivalising were incorporated in the theory. This was influenced by the process of selective coding, (see Section 4.5.5) which only commenced once the researcher was certain that Survivalising was the core category (Glaser 1998). The process of selective coding meant that the researcher ceased open coding, restricting coding to only those categories that related to the theory of Survivalising (Glaser 2004).

Theoretical saturation also delimited the categories (see Section 4.5.7) (Glaser & Strauss 1967). The process of saturation and method of theoretical sampling enabled the researcher to reduce the amount of data for coding to further define the theory of Survivalising.

Stage 4: Writing the theory

During this stage of the of Grounded Theory process, the researcher had accumulated coded data (interview transcripts and field notes), a series of memos and a substantive theory. The discussions in the memos provided the content behind the categories (Glaser & Strauss 1967), which became the major themes of the theory. For example, the major themes (section titles) were the core theory (Survivalising), and the four categories (Zoning-out, Bottoming-out, Self-realisation and Healing). Under each of these major themes the researcher discussed their properties (see Chapter Five). The process of writing began first by collating and sorting the memos.

Sorting

As stated by Glaser (1998:187) "sorting is the last stage of the Grounded Theory process, which challenges the researcher's creativity. In fact, it is the epitome of the theory generation process. Writing is merely a write-up of the sorting piles".

Although at this stage, the theory of Survivalising had an overall sense of conceptual integration, it lacked conceptual depth. According to Glaser (1978), if the researcher overlooks sorting, the theory may in general have integration, but it will lack connections among categories. Furthermore, if sorting is neglected, writing is

affected, as the researcher would find challenges in grasping the direction and sequence of theory development (Glaser 1978). The researcher spent a considerable amount of time sorting her collection of theoretical memos that had accumulated over a year. The process of sorting enabled the researcher to identify what she needed to write, and most importantly ensure that the concepts were theoretically organised (Glaser 1978).

The researcher began sorting by placing all her memos into a box. She began by picking a memo randomly from the box and placing it on to a worktable. The researcher then picked up another memo and compared it by evaluating how it related to the previous one. In this manner, the researcher continued to sort memos by their relationships with others. By constantly comparing their relationships the theory was enhanced in conceptual density and provided further theory integration (Glaser 1998). The researcher arranged memos by concepts (categories) and took care to ensure they were placed according to "best fit" (Glaser 1998:190). Accordingly, the process of sorting was followed by the straightforward task of writing up the sorted memo piles of analysis. In sorting, the researcher's intention was preparing her memo pile for the write-up of her results chapter (Chapter Five).

4.5.10 Theoretical Memos

Throughout the Grounded Theory process, but in particular, because of coding, the researcher wrote memos. The researcher was meticulous in documenting theoretical propositions that transpired in memos. Some of these were links between categories, or about the core category. As the categories and properties emerged, they and their links to the core category provided the theory. In effect, a memo was a note that the researcher wrote to herself on a hypothesis that emerged from a category or property, and particularly about relationships between the categories. Glaser (1998) makes the point that memoing is given a high priority; to the extent that coding should be interrupted to write memos (Glaser 1978). In using the Grounded Theory methodology the researcher assumed that the theory was concealed in the data and the mandate of the researcher was to discover it. Coding made the theory's

components visible, while memoing added to the relationships that linked the categories to each other.

To begin with, memos were generated from the constant comparison of indicators to indicators, then indicators to concepts. Subsequently, the process of memo writing actually generated more memos. R reading literature (once the core category was established) also generated memos, with the final process of sorting and writing generated further memos.

Memoing of a theoretical proposition took place regardless of the researcher's whereabouts, or the time of day a theoretical proposition would materialise. Often, the researcher experienced memo writing at night, and frequently just before the researcher fell asleep. Afraid that she would forget the idea/concept the researcher was forced to get-up and write, sometimes just a sentence, other times a few paragraphs and, at times, a reminder to write a particular memo the next day. Consequently, the researcher left a note pad and pen ready by her bed and carried a small note book around so she would not forget ideas that emerged.

Glaser provides a comprehensive guide in his books on how best to write theoretical memos (Glaser, 1998, 1992, 1978, Glaser & Strauss 1967). Consequently, to insure that the researcher followed his advice as closely as possible, she amalgamated these into one framework, which she used in memoing and called it the '23 Rules of Memoing' (see Appendix H). However, the researcher was conscious of Glaser's (1998) warnings regarding rules that could be restrictive and hinder memoing. Thus, the '23 Rules of Memoing' were merely used as a guideline rather then as a directive.

4.6 Researcher Bias

4.6.1 Literature review

During the researcher's first year of her PhD programme, and before selecting Grounded Theory, she conducted a literature review on the research topic. This

initial contact with the literature highlighted gaps in knowledge. It was clear that the majority of the studies were on treatments, quantitative in design and their samples did not encompass the homeless. Therefore, there was little evidence of an understanding of the homeless TB experience. However, at the moment of selecting the Grounded Theory method, the researcher became aware of the importance of stopping literature collection and ceased to review the literature to avoid contaminating or influencing the analysis.

The researcher did not know what literature would later be relevant, so the literature was not given a position of privilege, but instead it was treated as data. To prevent biasing the study procedures, Glaser (1978) recommends reading widely while avoiding the literature most closely related to what was being researched His concern, which the researcher also shared, was that the reading could constrain coding and memoing. To avoid this, the researcher followed the guidance of Glaser in actively reading other substantive areas. Glaser (1992:35) suggests that "It is vital to be reading and studying from the outset of the research, but in unrelated fields". Therefore, the researcher read widely, in areas such as business, teaching, psychology, sociology and international affairs. The researcher also read PhD theses monographs as this increased her understanding of writing at an appropriate style and level (Glaser 1992). This reading of "unrelated literature" facilitated in increasing the researcher's theoretical sensitivity in conceptualisation of data (Glaser 1992:35). However, during the final stages, when the theory emerged, it made sense to access literature, as it became relevant. This literature became additional data to compare and analyse (Glaser 1992). The progressive accessing and reading of relevant literature become part of the data collection procedures. Later the literature was "woven into the theory as more data for constant comparison" (Glaser 1998:67). As a final point, the literature review enabled the researcher to put the theory of Survivalising into the context of the existing body of knowledge (Chenitz 1990) and acknowledged the value of existing theories (Glaser & Strauss 1967).

The constant comparative method, as described above, deals with bias. Following Glaser's advice to stay open, enabled the researcher to avoid any initial bias or

adoption of a 'pet' theory. By following the Grounded Theory method systematically, the researcher was able to focus on what the participants were saying, allowing a relevant inductive theory to emerge. As with other forms of information, bias becomes "just one more variable" to compare (Glaser 1998:142). Glaser (1998:142) states that:

> The researcher realises that no matter how he may initially be distorting the data, as incidents are compared and the category patterns out the distortions will be revealed. He corrects the bias even if the slant may seem appealing to an issue to grind on or just personally compatible. He corrects even as he must code the usefulness of believing a bias on the part of the participant. Since these fictions have structural-functional power thy must be respected however trivial.

4.7 Establishing Rigour

During the research process, a number of measures were used to enhance rigour. Some of these methods have been described in earlier chapters. For instance, the researcher has articulated her personal views and insights about homelessness in Appendix A. The researcher has also specified how and why participants in the study were selected (see Section 4.4.2.1). The researcher has delineated the scope of the study, briefly in Chapter Three and in more detail in Chapter Four. According to Chiovitti & Piran (2003) these considerations and factors are an important and significant means for enhancing the rigour of the study.

There are many issues regarding the subject of establishing rigour in interpretivist research. Various authors suggest that for research to be valuable, rigour must be maintained (Guba & Lincoln 1989, Sandelowski 1993). The criteria for ascertaining rigour is reliant on ontological and epistemological underpinnings. Consequently, a Positivist paradigm is concerned with the criteria of reliability, validity, objectivity and generalisability (Guba & Lincoln 1989), while Interpretivism is concerned with the criteria of trustworthiness, which encompasses the standards of credibility, transferability, dependability, and conformability (Guba & Lincoln 1989).

Many authors have debated the criteria for evaluating qualitative studies (Tobin & Begley 2004, Chiovitti & Piran 2003, Sandelowski 1993, Guba & Lincoln 1989). Much of the debate between Positivism and Interpretivism, and truth-value, has already been covered in Chapter Three. The researcher does not attempt to represent the various arguments here, as it is not within the scope of this chapter. However, the researcher will identify the criteria that she used to evaluate the current study. Additionally, relevant issues related to criteria for rigour will be discussed and their application to this study illustrated.

Interpretivists have questioned the use of validity, reliability and generalisability to demonstrate robustness of qualitative research (Guba & Lincoln 1989). Tobin & Begley (2004) suggest that the change of terms across Positivism and Interpretivism paradigms could be seen as inappropriate. Nonetheless, they argue that rejection of the concepts of validity and reliability may deny the conception of rigour and thus weaken the notion of qualitative research as a systematic process that could contribute to the expansion of knowledge. However, as discussed in Chapter Three, Grounded Theory is a well established tried and tested method for systematic generation of theory from data.

The outcome of a Grounded Theory study is not concerned with the reporting of facts, but rather in presenting an integrated set of concepts in a theory grounded in the data (Glaser 1998). Like other qualitative methods, Grounded Theory uses its own specific criteria for establishing rigour (Sandelowski 1993). Thus, it is argued that it offers methodological completeness and a rigorous framework for data collection and analysis. In agreement, Glaser (1998:17) asserts that "Grounded Theory has its own criteria of evaluation". What is more, validity in its traditional sense is consequently not an issue in Grounded Theory, which instead is judged by workability, relevance, modifiability, and fit (work, relevance, and modifiability) (Glaser & Strauss 1967, Glaser 1978, Glaser 1998). These measures are related to the Guba & Lincoln (1989) criteria of credibility, transferability, dependability, and conformability.

To establish rigour, and meet the requirements set by Glaser (1978, 1998), the researcher maintained grounded theories criteria (fit, work, relevance, and modifiability). The criteria mentioned for the interpretivist paradigm of credibility, transferability, dependability, and conformability will only be discussed as they relate and apply to the current Grounded Theory study.

Credibility

According to Guba & Lincoln (1989), credibility relates to the value of truth in the findings. Credibility refers to the accuracy of the data obtained and establishing its trustworthiness (Chiovitti & Piran 2003). Namely, it questions the researcher's formulation of reality in expressing the various realities of the participants, instead of being identified by the researcher. Truth is accepted as participant based, rather then researcher based (see Chapter Three). In upholding this notion, Sandelowski (1993) purports that truth in qualitative research exists in the discovery of phenomena, and suggests that research is credible when interpretations of experiences discovered from the findings are clearly identifiable to those experiencing the phenomena. (Sandelowski 1993).

The criteria of *workability* relates to how well the concepts in the theory of Survivalising explain how the main concern or problems participants experience is being continually resolved. The use of Grounded Theory as a method enabled the discovery of the theory of Survivalising to emerge from the descriptions of participant's experiences in the substantive area of homelessness/TB. In essence, Glaser (1998:89) explains that Grounded Theory "…goes after the perspectives of the people involved".

Within Grounded Theory the criteria of credibility is also measured by what is described as *grab* (Glaser 1978, 1998).

During the journey the researcher experienced what Glaser describes as a *eureka* phenomenon (Glaser 1998), whereby the researcher could see Survivalising in many

other substantive areas and thus the concept had intense meaning. For the researcher, the eureka phenomenon was like a moment of clarity in which she could see the participants homeless TB phenomena from their eyes. Further corroboration came from other researchers that attended Grounded Theory workshops where the researcher presented her findings. It was apparent that others in the Grounded Theory training sessions could conceptualise Survivalising in their substantive areas. For instance, one participant could identify Survivalising among his PhD research participants. Further dissemination to health professionals from the host sites and other TB professionals (see Chapter Seven) confirmed the relevance and importance of the emergent theory of Survivalising. Consequently, this further substantiated to the researcher that the theory of Survivalising had "grab", signifying that the theory was relevant and people who heard about the theory recognised it. Glaser's (1978, 1998) criteria of *relevance* was achieved because the Grounded Theory method allowed the participants main concern (Survivalising) to emerge from the data rather than from preconceived ideas. As maintained by Glaser (1998), a relevant study contends with the real concern of participants, and captures the attention of people because of its grab.

However, Glaser (1998:104) warns against the problem of forcing, which could undermine credibility, and states that: "it is easy to see a core variable everywhere and easy to force other data". Thus, to avoid this predicament and ascertain credibility, it was important to make sure that Survivalising was based upon emergent fit. This was confirmed by the method of constant comparisons applied in analysing the data (see Section 4.5.8).

To further establish rigour, it was important to validate the findings with participants. Thus at the end of the interviews the researcher offered to return at a convenient time for the participants and show them the transcribed interview to check that they were satisfied with the transcript and that their descriptions of their experience was accurate. Although this form of 'member checking' was offered, none of the participants sought validation of their transcripts. The researcher was concerned with this, and after consideration felt the need to pursue member checks with the

participants on the emerging theory. Finally, this was accomplished by discussing the theory of Survivalising, its phases and their properties, with some of the participants. Participants confirmed their main concerns and described their experiences during each stage of their homeless TB phenomena. This form of checking was more successful, and provided a good opportunity for the validation of the theory and further means of constant comparison.

Modifiability improves the credibility of a Grounded Theory study. This was achieved again through the constant comparative method of the research process, whereby the researcher constantly compared incidents with incidents and incidents with concepts, whereby the theory was modified by the emerging data and inaccuracies were assessed and rectified. As argued by Glaser (1978:7), a Grounded Theory is never right or wrong, it is ideational and the "conceptual idea is its essence". In other words, the theory of Survivalising, which emerged from applying a Grounded Theory approach, produced credible findings as a result of the correcting nature of the constant comparative method and the prerequisite that the theory has workability (Glaser 1978).

According to Guba & Lincoln (1989), credibility of findings is enhanced through protracted engagement. In this study, data collection occurred over a prolonged period (March 2006-February 2007). This is coherent with Glaser's recommendation of conducting intensive fieldwork to discover participants' main concern and he indicates that a Grounded Theory study can take roughly a year to carry out (Glaser 1998).

As recommended by Chiovitti & Piran (2003), observations were taken from fieldwork, following interviews. Credibility was enhanced by the researcher describing and interpreting her experiences in the field notes. The researcher kept a file of field notes in which she described the content and the process of interactions, including significant aspects of the interview experience and participants reactions to various discussions.

Transferability

In respect of transferability, Guba & Lincoln (1989) consider the measure of fittingness as a criterion against which qualitative research should be assessed. However, the Grounded Theory meaning of the term *fit* Glaser & Strauss (1967) and Glaser (1978, 1998) is different from Guba & Lincoln's (1989) version.

Relating fit to transferability, Guba & Lincoln (1989) suggest that this criterion is achieved when the study findings can fit into other substantive areas beyond the study context. They propose that fit is established when the study findings are meaningful to those who read it and relevant to their experiences. As described above, the uses of the term 'fits' relates more to the criterion of credibility. Glaser (1978, 1998) advises that fit relates to how closely concepts fit with the incidents they are representing. Consequently, this is connected to how thoroughly the constant comparison method was carried out. Transferability is accomplished as the theory is constantly being corrected through constant comparisons.

Glaser (1978, 1998) argues that for a truthful and dependable study, the researcher should never force or select data to fit preconceived concepts. He emphasises that truth and dependability occur when concepts and are not forced on the data and the grounded theorist discards ill-fitting concepts. This allows the true theory to be discovered by constant comparative analysis. This method ensures that concepts fit and are inductive and grounded in the data. Emphasising this, Glaser (1978) states that constant comparative analysis is about emergent fit, thus non-grounded hypothesis should be discarded.

Guba & Lincoln (1989) indicate that transferability is comparable to the Positivist criteria of generalisability. They propose that qualitative researchers provide comprehensive descriptions to allow other researchers to establish the fittingness of the findings. As described above, transferability, according to their criteria, is the extent to which the findings 'fit' into the contexts outside the study. However, while saturation was reached, the sample size of the current study of 16 participants is considered small, and in this sense cannot uphold the criteria of generalisability.

Findings from this study should only be viewed within the homeless/TB context. Furthermore, as discussed in Chapter Three, it was not the intention of the researcher, or the aim of current study, to establish generalisablity, but rather to discover the participants meaning of their phenomena (Homelessness/TB).

The aim of Grounded Theory is not about gaining detailed description of phenomena, but rather conceptualisation of the phenomena. Glaser (1998) claims that, unlike other methodologies, Grounded Theory is distinctively transferable because of its theoretically abstract nature. What is more, Grounded Theory does not carry with it deeply debated problems such as lack of transferability, as its intention is conceptual rather than descriptive. The abstract conceptual level of Grounded Theory of time, place and people make it a modifiable theory.

Although there were no directly comparable theories of Survivalising in the literature, there were some studies that support properties of the theory (see Chapter Six and Seven), providing support to the findings of the current study and demonstrating a degree of transferability.

Dependability

Guba & Lincoln (1989) propose that dependability can be verified by the method of audit. The researcher was conscious of her obligation to maintain transparency and openness throughout the research process and thus kept an audit trail. This provides a clear understanding of how the researcher arrived at the interpretation and enables the researcher to scrutinise the research findings (Auberbach & Silverstein 2003). The audit included include data, findings and interpretations. In the current study, the audit trail was managed as an *Excel* document, encompassing six major features. This catalogue included, participant reference, raw data, connections between conceptual categories, substantive and theoretical codes and the properties of the categories. As a result, the researcher is able to provide evidence that the theory of Survivalising is grounded in the data and is internally consistent (see Section 4.7.2).

Confirmability

According to Guba & Lincoln (1989), the method of keeping an audit is also used to assure confirmability. In fact, it is the main mode to ascertain confirmability. In addition to what has been discussed above, analysing the audit trail in the current study is a basic undertaking for Grounded Theory. This is mainly because of Glaser's (1998) disproval of using computer software for data management and analysis and his advice about being close to the data. Glaser (1998) contends that the audit trail for a Grounded Theory study should simply consist of raw data, coded data, memos, lists of codes and categories, and the composed Grounded Theory. The researcher maintained an audit directory in the form of hard copies and computer files. This included all the raw data transcripts, field notes, memos, lists of emerging codes, and categories (see Section 4.5).

Confirmability is also connected to the researcher's role in providing clear explanations of how the research was conducted so that others can confirm the results. The earlier sections of this methods chapter provide an additional means for others to validate the conduct of the current study.

In addition to imparting the methodological technicalities and procedures utilized, Chapter Five presents the research findings and provides a grounded presentation of the study results. Although the researcher could not present all the narrative data from the study, the researcher made an effort to present as many of the direct voices of participants, in the form of quotes, a reasonably possible. This enhances the study's trustworthiness and confirmability by highlighting how the current study was guided by participants and enables the reader to confirm the results. Even though not all the data are included in Chapter Five, they are available for audit.

Trustworthiness was further enhanced by the researcher checking the theoretical constructions generated against participants' meanings of the phenomenon by member checking. Finally, the use of participants' actual words in the theory provided groundedness in the substantive area of the study.

Confirmability of findings was also obtained through regular discussions and deliberations with the researcher's supervisors. Peer de-briefings about field work with the supervisor's facilitated improvements, particularly regarding interviews. Early interview transcripts were reviewed and the meetings established whether leading questions had unduly influenced the response of the participants. This assessment process enabled subsequent interviews to improve in their quality and provide a further means of establishing confirmability.

4.8 Conclusion

In summation, the current study used the Grounded Theory methodology as developed by Glaser & Strauss (1967) and Glaser (1978, 1996, 1998, 1999, 2001, 2002). In upholding a qualitative design to this study, the researcher worked from the viewpoint that the research findings were the result of an interpretive effort and were subjective rather than objective (Denzin & Lincoln 2000, Glaser & Strauss 1967, Walsh 2003). The researcher recognised that she was part of the research process and thus affected the results. The Grounded Theory method was valuable in discovering the theory of Survivalising, which was grounded in data from a substantive area where little was known, and scarce research had previously taken place. The classic Grounded Theory method and procedures determined the research process and was used to substantiate rigour.

PART III

A theory is the more impressive the greater the simplicity of its premises, the more different kinds of things it relates, and the more extended its area of applicability.

Albert Einstein, cited by Calaprice (2005:246)

Concepts are simply empty when they stop being firmly linked to experiences

Albert Einstein, cited by Calaprice (2005:226)

CHAPTER FIVE – RESULTS - THEORY OF SURVIVALISING

"When I was going through the drugs, and being on the street, I didn't care whether I lived or died. I was just living day by day and just surviving. I didn't think about my kids. I didn't think about her. I didn't really think about myself. I was just surviving and just smoking (crack cocaine) to get out, trying to get out of this circle or whatever I was in. But I end up going into the hospital, and they say everything for a reason. Maybe I needed this TB to get the start I needed, so that I can get a flat and that. Cause this bed-sit is a start, then I'll be able to have my kids on the weekend and spend more time with them" (40-year-old male, temporary bed-sit[14]).

5.1 Introduction

This chapter presents a theory grounded in interview data collected and analysed using the Grounded Theory methodology. This stemmed from the work of Glaser & Strauss (1967) and Glaser (1978, 1996, 1999, 2001, 2002). A grounded theorist strives to understand the participant's main concern within the substantive research area (Glaser 1978). The purpose of this research was to develop a theory that would provide insight into, and a clearer understanding of, the experience of being homeless with TB in London. The study aimed to deal with gaps in knowledge by seeking to address the following research question:

> What does having tuberculosis mean to homeless people and how does this impact their opportunities to complete treatment?

To answer the question, an in-depth exploration was undertaken of the experience of homeless people diagnosed with tuberculosis, how homeless people deal with these issues and how this impacts upon their taking TB treatment. A substantive theory emerged from the data. This chapter presents a description of the theory of *Survivalising* and its stages.

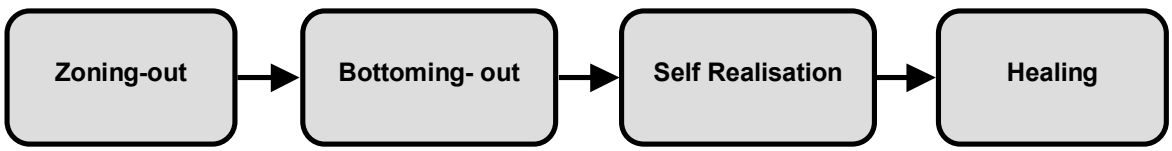
[14] Bed-sits are one bedroom temporary accommodation, which are sometimes used by homeless people.

Early on, during the interview process, it became clear that there was much more emerging in the substantive area than the issue and concern of TB itself. Homeless people had bigger and deeper issues that were their main concern. Essentially, they needed to deal with and manage their complex existence, everyday survival and the harsh conditions that they faced. Although the issue of TB was expressed in some of the findings, it was not the core issue. Analysis of the data led to the formulation of the theory of Survivalising, which presents a model that reveals and describes a basic social process[15] that homeless people engage in.

Survivalising is a pattern basic to the organisation of social behaviour, occurring over time for homeless people diagnosed with TB. This process is conceptualised as a number of social patterns, encompassing physical, psychological and social phenomena. In this chapter, within the context of the research findings, the researcher will conceptualise and describe the categories of Survivalising, their properties and their conditions.

This newly discovered basic social process coined here as Survivalising includes four distinct social patterns or categories: Zoning-out, Bottoming-out, Self-realisation and Healing (see Figure 4). To provide a grounded context and a direct voice from the homeless participants, quotes from interviews are used to illustrate the process of Survivalising. The following section provides a brief description of the Grounded Theory of Survivalising, which is subsequently explained and exemplified conceptually.

Figure 4: Survivalising



[15] "Basic social processes are processural…they process out. They have two or more clear emergent stages" (Glaser 1978:96-97).

Each participant had their own story and each was unique, explaining how they became homeless, their daily lived experience and so forth. However, despite their varied backgrounds, there was a clear common pattern in the experience of homeless people. Survivalising emerged and re-emerged throughout their narrated experiences. This consistency formed the theory that was grounded in the data presenting Survivalising as their main concern. Survivalising is the core category and captures the culmination of the entire social pattern that individuals engage in and explains this social process.

Survivalising is not merely about survival, as survival is a distinct end point that is not always achieved by this vulnerable group. Survivalising is a holistic and complex process about dealing with, and managing the adversity of homeless life, which makes life bearable for these individuals. The concept of Survivalising is a transcending phenomenon, and like the homeless people themselves, it is not homogenous. Rather it is heterogeneous, as it modifies and transforms amid social, psychological, physical/medical influences, and is affected by many variables.

The theory of Survivalising provides a new tool to understand the growing problem of TB among the homeless. There are profound implications for the care of homeless people diagnosed with TB, which will be discussed in more depth in Chapter Seven. Although the process of Survivalising has much 'grab' and could be studied in other contexts and substantive areas for example, in single parent, or PhD student Survivalising, and a formal theory developed, the scope of this chapter merely covers the direct findings from the current study. In Chapter Seven, the implications and recommendations will be explored.

5.2 Categories of Survivalising

The process of Survivalising begins when the individual is, in essence, absorbed in the process of *Zoning-out.* Zoning-out is characterised by drifting. This describes the daily quest to survive the complex realities of homelessness, addiction and social exclusion. Individuals often engage in substance abuse, forming a chemical comforter for the stigma, fear and harsh conditions of homelessness. This is often

financed through commercial sex work, begging or petty crime. Personal health is neglected, overshadowed by the immediacy of survival and escape. TB diagnosis is often concealed, fearing further stigma and discrimination, and seeking TB treatment is a low priority.

Bottoming-out is described as a personal crisis point. At some point, a crisis of profound nature shifts the individual to a new state propelling them to a rock-bottom condition. During this stage, individuals experience an acute sense of vulnerability, anxiety and fear. Admittance to Intensive Care Units, or the shock of TB diagnosis, results in individuals hitting an all-time low. They find they are no longer able to view themselves, or the world, in the same way. This event is a critical juncture for the individual and can form the catalyst for positive change.

Self-realisation is a crucial turning point in which individuals critically assess themselves, their lives and their future. A new conceptual order is accepted and fundamental attitudes toward life and living are transformed. Undergoing self-realisation results in an increased clarity of personal needs and the will to pursue them. Interest in seeking health and other social services increases and adherence to TB treatment improves.

Healing is about individual concerns for *normalising*, influenced by re-socialisation and changes in psychological constructs, which leads to a new personal direction. Healing is about mending a fractured existence, restoring health and building a new and better life. Concerted efforts are made to engage with social service networks, to apply for housing and to rekindle family and social relationships. Health and adherence to TB treatment become a priority.

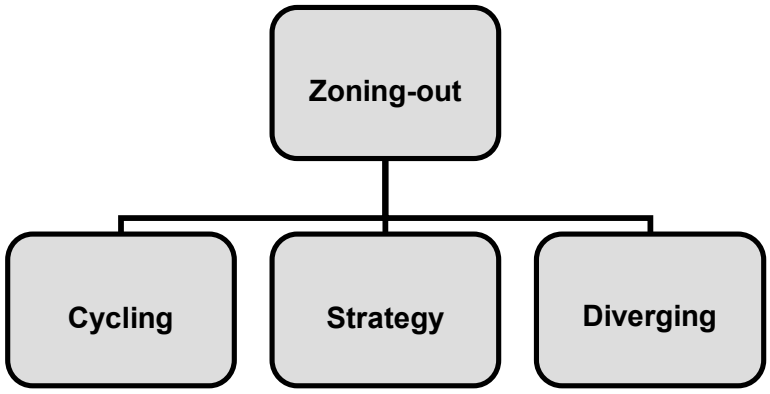
As discussed earlier, all the participants were absorbed in the process of Survivalising. However, the degree to which individuals were zoning-out, bottoming-out, self-realising or healing was dependent on their unique experiences and the different adversities they faced. At the time of data collection, six individuals were zoning-out, three were bottoming-out, two were self-realising, and five were in

the process of healing. Nonetheless, those who were immersed in the process of healing were able to provide retrospective data on the entire survivalising process, including zoning-out, bottoming-out, self-realisation and healing. Others, who were for instance in the process of bottoming-out, were able to provide data on the experiences of zoning-out and the move into bottoming-out. Those at self-realisation could provide data on both their experiences of zoning-out, bottoming-out and their current state of self-realisation. Subsequently, participants during different phases were able to provide comprehensive and in-depth detail into the various phases and concepts.

5.3 Properties of Zoning-out

There are three significant properties that encompass the concept of zoning-out. These include the properties of *Cycling*, *Strategy* and *Divergency (*see Figure 5). Although these three properties are unique elements in themselves, they are interconnected and each is important in understanding the concept of zoning-out.

Figure 5: Zoning-Out



5.3.1 The Conditions of Cycling

Cycling is a complex process in which homeless people who are zoning-out are engaged. Cycling is about what confronts the individual in their social world, for example they may be moving from place to place or sofa to sofa. It is about getting on with their lives, however complex and harsh they are. In reality, the world is

passing them by, while they remain in a state of cycling, drifting day to day. The paradox is that cycling is a phenomenon of motion, yet the individual remains in a stagnant state. Individuals drift from one day to another and live every day as it comes. Furthermore, there is no such thing as a 'typical day', adding another obstacle in their way.

> *...I just try and make everyday what I can make it y'know. If it's good it's good, if it's bad it's bad…I just go through everyday as it comes (P7)*

> *...there really wasn't such a thing as a typical day…You couldn't really plan ahead and everyday was pretty much the same, just a case of strolling on by, doing what you had to do (P6)*

> *It's jus that's the circle, that's, all there is in life (P2)*

> *It's a vicious circle (P5)*

Individuals who were experiencing the state of zoning-out discussed making the best of their difficult world. They live their lives each day as it comes to them, often within a passive existence. *Cycling* therefore describes the condition of the homeless TB sufferer as a vicious circle, taking whatever life throws at them.

Cycling could be viewed as an egocentric type of existence, whereby the individual is unable to conceptualise the impact of their actions on other people such as family and friends and thus cycling is merely about the individual and their self-survival. The lack of social support means that the individual is left to merely think about themselves and conceptualise themselves in an egocentric world. Although it could be viewed as a selfish state, in reality the individual does not necessarily think about their own well-being, because this is overtaken by the need to get by in their world in any way possible and thus what may actually be best for the individual is put to one

side for basic survival. The fierce motion of cycling makes rational thinking difficult, and planning for the future is sidetracked ahead of day-to-day confrontations and struggles.

The phenomenon of zoning-out does not appear to have a set time frame. For instance, some individuals may continue for a number of weeks or months, while others have been found to be cycling for more then 20 years, drifting from one place to another.

The unpredictability of homelessness is a problem for individuals who constantly cycle and move around. Nonetheless individuals who stay in an unchanged state, are in essence a victim of their uncertain and rough environment. Often they do not have housing or know where their bed is for the night and this uncertainty is problematic for the individual and they constantly cycle to find shelter and a safe place to sleep.

> *I've been homeless on and off for 22 years…I've been moving from one place to another…normally I'll sleep at friend's here-there-and-everywhere (P2)*

> *I was on the streets for twenty years…miserable, in and out of hostels… (P10)*

> *…I found myself on the street, and like nowhere to stay actually. Sleeping in blocks of flats, trying to stay in shop corners and wherever I could find somewhere where it was warm to stay. And during the day I would walk about, I sit on tubes, you know to get some kip cause sometimes I couldn't sleep at night (P5)*

As described earlier, the sense of uncertainty felt by individuals who are cycling creates depths of insecurity and stress. For instance, the loss of basic shelter not only means that the individual loses a roof over their heads and warmth that comes with it, but personal belongings are also lost when the security of housing is gone.

I was staying with a mate of mine for about a year on and off, and one day she decided to boot me out with all my stuff. I had nowhere to go; I had five bags of luggage…And you've got no money, and you're standing there embarrassed…It's horrible…everyone's looking at you like, look at her she's homeless…You lose your possessions cause I'm travelling all the time. Things, important documents, important things to you lose, because you're staying place to place…If they throw you out, so what are you going to do then? (P12)

Being homeless, particularly if the individual were a rough sleeper, has a major impact on basic needs such as finding food and shelter. All the individuals found it very difficult to cope with being homeless.

You need to eat, you don't have any food to eat, you need to sleep, you don't have any place to sleep, you feel tired. You don't have someone to tell you how are you? (P14)

It's not very nice really when you're homeless…being homeless is a horrible thing… for people like us it's the way it is (P12)

My life not very easy, very, very hard for me…everything hard for me, hard life (P9)

Living on the streets was horrible. Really was some rough times, you see some horrible things (P11)

In general, a great deal of violence is inflicted upon these individuals, but it appears to be most common among those who are zoning-out. The violence experienced is also very extreme, especially when living on the streets or in hostels. Immense danger was felt and the individuals talked about it as a horrifying and traumatic experience. The causes of violence were varied, resulting from a range of sources,

which included the criminal drug scene, the general public and other homeless people. It was a constant and unpredictable daily event, from which it was difficult to escape. Dealing with violence is in the cycling condition. Individuals talked about life being about fighting, theft, constant hassle and trouble wherever they were.

A lot of things happened to me when I was on the streets. I came close to death so many times, I was getting beaten-up by people, I got kidnapped, I had a gun held to my head…they were trying to kill me…(P3)

When you're sleeping rough, you're an easy target…people are drunk some people just like violence to other people (P6)

They're all fighting, constantly, there's a fight every day. I don't know why, always fights everyday, man…they're all fighting through drugs or through drink or through who each owes money or whatever… (P10)

The possibility of rape or murder is a constant fear, clearly articulated and expressed within the condition of cycling by individuals, particularly female participants.

…anything can happen to me. I can get raped, I can get killed… (P2)

Or if I go to stay on the steps and then sleep, the police are gonna come can give me a handful. From there or from that step or from that block of flats, so I'm just walking the streets at night. It's very traumatising. What can I say about it? It's just not a good life. It's a lot of fear… (P7)

A number of individuals described mistreatment by the authorities.

> *If I leave it there too long [personal belongings in squat] they come an clean the flat out, the council throw everything away. I've lost many things over the years, many things I've lost. And that's the thing that gets me down and give me the none carry on feeling…Even this place this place where I am at the moment [squat], they'd call the council or they'd call the police, to come and get us out, and then we're back on the road again (P7)*

The majority expressed various and deep rooted fears. They constantly felt the need to look over their shoulders, because of the risk of indiscriminate attacks. Violence from theft was significant in their daily lives, affecting their sense of security. This cycle of fearing, impacts on their basic needs such as sleep.

> *I was scared and I feel alone…I don't even know how to describe it, you gotta keep looking over your shoulder (P2)*

> *I couldn't sleep in case, case someone crept up on you, or just the people who lived there telling you to move (P3)*

> *All I want them to give me is a roof, it could be a small cupboard man. So then I can be alone sometimes, or more contented, cause sleeping on the steps and things like that, you can't get a good sleep, because you don't know who's gonna come and mess with you, or steal your things, just worried about the people around… I've had trouble before, people on steps come up wanting to put a knife to you... And if I'm walking the street at night the police stop me and ask me where I'm going, why am I walking the street, and this and that…Life is very rough… sometimes I don't sleep four or five days. Sometimes I can't keep up no more and I collapse and people come and even take my coat off or come take my shoes. Or wake you up and threaten you for some money, where you hid your money? or where's your drugs? Or if I've got food in my*

rucksack, they'll take it. If I'm sleeping on top of it for a pillow, they'll slide it off my head, because I'm so tired now, I've gone into like a coma sleep, when I wake up in the morning every things gone (P7)

Sleepy all the time and just tiredness all the time. It really does my nut in cause it means I can't even do day-to-day things... I want to do something but I'm too tired for anything else, just feel as though I'm jet lagged…It's a horrible feeling, because I know I want to do something, but I just get so tired I can't (P10)

The fear of police involvement in day-to-day life also appears to be a problem for some individuals. The constant pressure from police to move from one place to another made coping difficult and proved to be a daily hassle.

It's almost impossible to get a decent night sleep. Police are always moving you along…If you're sleeping on a park bench the police find you there at night they'll move you on (P6)

It's hard coping even now, it's hard coping. I'm out there, cause everywhere I try, if I'm sleeping in a corridor or I've found a squat, police will come along and tell you to "move on, you can't stay here". Where can I go? Even if I just sit at the bus stop sometimes I'm curled up in front of the bus stop sitting on that red thing there they say I'm loitering and I've got to move on. Where can I move on to? I then just move on to just down the road and then there's a bunch who tell me to move on there. Y'know it's not nice at all. And that's what makes you don't care if you live or not (P7).

Individuals often felt that they were hidden from help and that others have no sense of care for them.

> *I'm not getting no help from any of the people…I just have this don't care feeling, I just feel like to give up, and just carry on the way I am… the help, it's just missing me, that's what I feel (P7)*

> *…nobody seems to care. Nobody seems to want to help me…I just need somebody to give me the opportunity. But at the end of the day I just need a chance…Not gonna get help…I ask for a better help, and I can't even get it. Just want better help (P10)*

The impact of cycling is emotionally devastating to the individual. At an internal level, individuals feel 'broken' and incomplete. Furthermore, the psychological burden of homelessness is compounded by concerns of loneliness and a sense of isolation from the rest of society.

> *When it's in the winter, you feel hard, every ones going home especially at Christmas, family gets together and you're the only one that's walking around freezing cold, wondering where you're gonna put your head down, just feel lonely, feel lonely on your own and no one cares, and you just feel left out…I was scared and I feel alone (P2)*

At the same time, individuals were anxious about their isolation and about their lack of personal space and desired their own space. This seeming paradox reflects the confounding and complicated state of cycling.

> *I'm so use to doing what I like to do, going when I want to go, without having to tell. I need that little space sometimes and I'm not allowed to have it…I need my own little space, my room…(P2)*

...I want to live in my own space again… (P3)

The sense of isolation and daily fear and stress impacted upon the individual's self-esteem. When individuals talked about themselves, they were often denigrating and it became apparent that this affected their physical health, particularly in adhering to TB treatment. They also felt suicidal and that their life was worthless.

I don't feel so good about myself I jus feel I've wasted. I don't care about myself enough; I jus don't care about myself enough…(P2)

I just feel like taking my life, and I would have tried it one time, tried to do the suicide one time. I took 30, 32 paracetamol. And I thought bloody hell, and they found me just lying on the steps, just curled up on the steps… I was doing myself out. It's not very nice, it's a very rough life y'know (P7)

Eleven years ago I make suicide attempt. Even tried for suicide, I wanted to kill myself, I can't do that (P9)

5.3.2 The Conditions of Strategy

During the zoning state, *strategy* is the individual's way and method of dealing with their situation. Strategy is an important property of zoning-out, and forms the individual's way of dealing with the cycling of homelessness. Social norms are set aside as the individual takes up intense activities, which at times are costly in their psychological, social and physical consequences. They attempt to deal with their social world by finding methods to cope day to day. The majority of individuals were using substances as their strategic coping mechanism. Individuals varied in their substance use, some had multiple drug habits, including crack cocaine, heroin and alcohol, while others selected one form of a chemical comforter such as alcohol or marijuana, using it exclusively.

The degree of zoning-out is different from one individual to another. Some individuals were in such a deep zoning state that they could barely function, communicate and thus engage with people, while others were in a lesser state of zoning and more able to interact in their environment. For instance, those that were absorbed in multiple substance use such as with crack cocaine, heroin and alcohol and involved in criminal activities or commercial sex work were more deeply zoning, while others that were having some alcohol to numb the cold and/or to forget about their lives were zoning-out to a much lesser degree.

Strategy provides individuals with a way to deal with their social world. They take part in activities that assist them to cope by forgetting or numbing themselves against their physical but also psychological environment. Individuals find comfort in the chemicals they take. Although such acts are seen by some as deviant behaviour, a closer look shows that in fact these are activities of Survivalising for these individuals.

Substance use provides a brief escape from the torment of homelessness. It is a short-term deadening of the physical and psychosocial pain of homelessness. This momentary escape is achieved by the individual as he drinks alcohol, takes crack cocaine, heroin or another drug of choice. Then he or she no longer feels his/her self; no longer feeling the pain and stresses of homeless life- they achieve momentary numbness. The individual does achieve a sense of numbness and a brief reprieve and break from the hectic homeless world, but they come back from this intoxication and find everything as it was before, and nothing has changed. This is what can be described as a vicious circle of existence, which it is immensely difficult to overcome, as they get caught up in the process of zoning. The individual merely tricks themselves by eluding and hiding from their living reality, but in this process they lose their identity.

By engaging in an activity such as substance use, the individual deliberately aims to absorb themselves in a state of escape.

I wake up and in the morning I just have a drink to blank everything out. I don't want to think about it. I know it's not right but it's just you drink…I do it to forget about (P10)

…having a drink with the guys…having a good old smoke having a laugh and that makes me happy…I smoke Rock, I smoke Brown, and I drink a lot lot. And I enjoy drinking a lot…That's my typical day, drinking and smoking…I love it, but I know it's not good for me [giggle] too much and smoking too much, I've not stopped for three days (P2)

I'm an alcoholic, I drinking, all the time, beer, beer, beer…I've been drinking, eight years…no wine no scotch, just a beer…if somebody give me, I drink if somebody not give me I won't drinking…I buy beer, not the strong one, I have four maybe five, drink it slowly, slowly… Sometimes I'm lost in my beer (P9)

The interview findings often painted a bleak picture of participants' lives. Although the individuals in this study lived in a range of circumstances, they all showed similar ways of dealing with their difficulties. With the immense problems associated with the phenomenon of homelessness, it is understandable that individuals find coping difficult. The difficulties in coping with life require the individual to seek solutions themselves.

…cause that's the only thing that I depend on to make me feel alright [crack cocaine], in the life that I'm living you see. Not that I want to keep on taking drugs, but that's the outlet of I don't know this life that I'm living…That's how I cope [crack cocaine]. That money that I got, go to waste on the drugs….I was just smoking [crack cocaine], and just carrying on. That's how I cope. That money that I got go to waste on the drugs (P7)

The ability to cope with adversity is suggestive of resilience, but their strategies for coping, seeking comfort in substance use leads to isolation rather than to their seeking help.

My life is just drugs y'know. That's just my life (P7)

Everyone has basic needs that need to be met for a productive life. However, individuals in this study had significant problems in attaining basic needs such as food and shelter.

Although individuals realised the seriousness of not eating and that it could lead to health problems, the recurring compulsion to engage in substance use outweighed the desire to look for food; because they were involved in substance use, it meant that some individuals' daily activities revolved around the acquisition and use of substances.

The basic needs of individuals are controlled by the property of strategy within zoning-out. This can be clearly seen when individuals articulate that their first priority of the day is to take a substance to make 'living' the rest of the day possible.

Eating as well is difficult…so you use to eat just depending on what I was doing, where I ended up (P6)

First thing when I get up, the first thing I do is I think about having a drink…I get myself ready prepared, and sometimes I don't even bother, I just want to get a drink and I go out and beg or something some money for a drink, and I took first thing and I took last thing. I think about drugs, how I'm gonna get drugs? I get it somehow, one way or another. That's just my typical day, drinkies all day. That's all I do all day long, just drink and smoke (P2)

Substance use created problems with relationships. Participants seldom talked about close or important relationships with other people in their lives. Although some described informal relationships with 'friends' which were actually other substance users, they were not viewed as trustworthy friendships. Such 'friendships' were seldom either reliable or unconditional. In fact, the relationship with other substance users was often one of distrust, occurring because of the violence frequently experienced in the drug underworld, where fighting was commonplace. Developing meaningful relationships were affected by their conceptual ordering of substance use, which became their main priority.

Furthermore, the findings indicated that substance use and crime were related in many ways. In some cases, substance use led to crime, which increased stress and was an emotional burden on individuals who described the criminal drug scene as a horrific and dangerous underworld. The homeless rely on themselves and substances since they do not have a social network providing support.

> *I've got certain friends around me that's not good [substance users]…with a lot of my friends, they still get messed up because of drugs… (P7)*

> *…these days now, especially in the drug screen, there's a lot of arguments and free arguments, for no reason and a lot people, get damaged or killed. And for nothing at all. Over a pay or crack, you borrowing this and don't give it back and things like that (P7)*

> *You can't trust people around you…I wouldn't wish the street life on, on no one. The amount of friends that I've lost, the people that have died and that, being on the streets it just ain't a nice game. You meet some horrible, wicked and evil people and they are just right evil, no matter what you do for them. Right horrible people… (P11)*

Within this phenomenon of Survivalising, individuals find themselves extremely 'busy' with maintaining their zoning-out state through substance use. This state of 'being busy' for the homeless individual is found throughout Survivalising. Those zoning-out are busy taking substances and finding money to pay for their addiction.

> *I cope with it by keeping myself busy. You may not understand, but once I'm smoking, yeah it's continual, day and night, smoking, nothings bothering me I don't have to care about anything. But when I stop, and then, ha once I stop, all thoughts comes back to me, and what am I gonna do, and I'll be like, I have to be doing something, I think if I stop doing something I just go completely mad, so I have to keep myself busy, drugs drinking, getting drunk (P2)*

Maintaining the strategy for zoning-out is challenging and homeless individuals had to do things they did not want to do, but they felt it was important to do these things to get by. Commercial sex work, begging, or theft become methods for financing substance use and become part of the zoning condition. The conception that it is merely deviant behaviour appears erroneous, because the narratives indicate that begging, commercial sex work or theft are not easy because there is much personal risk to the individual whether of violence, HIV, or prison.

> *I was doing prostitution to support my drug habit. I was doing whatever I could (P3)*

> *In that situation, for you to support your habit and smoke (crack), you've got to do things that you don't want to do. You got to risk your freedom which could end up with you life. You're forever doing things that you don't want to do, but you've got to, you've got to survive ain't you? (P11)*

> *Begging jus sitting down on the street, all day, just begging. It's hard to explain really, you can't y'know, thieving, shoplifting, cold. (P4)*

The condition of strategy can cause a challenge to the individual, because although they may have a desire to stop substance use, zoning-out becomes a difficult chain of events to break, due to the fear of substance withdrawal. Another aspect of the fear encountered within zoning-out is through the experience of substance withdrawal, which encapsulates and traps the individual in a state of zoning-out.

> *...My main concern was getting drugs, feeding my habit. That was number one. That comes before anything, because remember heroin is a physical addiction, you don't want to be out on the street and you're ill [withdrawing] Y'know that pain is horrible it hurts [withdrawal from heroin] so the first thing you've got to do is secure your habit. And that use to be the first thing on your agenda, is get money to get your heroin (P11)*

> *But that's kinda the only worrying thing cause you got to make sure anywhere you are in the country, you got to get to the chemist to get your methadone cause if you miss it, you know you get this ill feeling (P7)*

5.3.3 The Conditions of Divergency

Diverging is a property of zoning-out and formulates the conceptualisation of 'having no limits'. It encompasses an important condition within the process of zoning. A number of elements are involved in this sub-concept. It is about individuals separating themselves from others by the direction they take and by their divergent sense of self. The individual digresses from prescribed social norms and identities. Due to the conditions of cycling and strategising, the individual finds themselves in a process of diverging which leads to stigmatisation.

The homeless themselves describe homelessness as a different way of living. At an internal level, the individual feels different to non-homeless people. Often they feel like a 'misfit', unable to fit into the 'normal' world existing around them. The individual experiences a social divide, between the homeless and the non-homeless.

This segregation from 'normal' society leaves the individual feeling detached from 'normal life'.

> *It's a different way of living… [homelessness] (P6)*

> *No one cares…I don't feel like everybody else, I feel different. I feel like there's two set of people, and I'm one and then there's. I can't really put into words, but I don't feel like I fit in anywhere like in the normal life, I just don't feel like I'm a normal case, it's been a long time since I've had a normal life (P2)*

With this different worldview of themselves and others, the homeless individual develops feelings of being different and 'un-normal' in comparison to others. Many of the individuals compare their lives to that of non-homeless people and illustrate this with the constant problems they encounter in their lives. Life for the homeless person is difficult and things that non-homeless people take for granted everyday are marvelled at as mere daydreams and unreachable realities by the homeless individual who is zoning-out. These notions include holidays and relationships that provide us with a social support network such as husbands, wives, girlfriends or boyfriends. Within this state of divergency, individuals also contemplate the idea of swapping their homeless life with that of a non-homeless individual. The sense of difference and their comparisons leave the individual feeling unhappy and stressed with the burdens they face daily.

> *That's probably the way they look at us [homeless/non-homeless] (P12)*

> *I tell you…maybe you have a car, maybe you have for bus money, I have nothing…I can't live my life very easy. For you its very easy, you go for school, you go maybe for holiday, maybe you have husband, maybe you have boyfriend. I'm not happy… (P9)*

I want a new start. I want to be happy. I wish there was somebody I could swap with, swap lives just for one day, so I can see what I've got a good thing, but I wouldn't like to give that to somebody, because it's horrible, it's a burden…It's a burden to somebody else. Well, I wouldn't like to put somebody through what I've been through, just for one day. It wouldn't be fair (P10)

However, individuals are left with the summation that they form a distinct social identity; that of a homeless person. Individuals come to the conclusion that non-homeless people do not care about them. Some even thought that non-homeless people might be jealous of them because of their 'free' lifestyle.

Individuals recognise the divergency between themselves and other non-homeless people. Although they often feel a sense of not being 'normal' when they compare themselves to others, there appears to be a deep need to counteract the divergency. For instance, some people turn their shelter into a 'home' by furnishing it with items found on the street, to resemble a 'normal' house, while others make sure they always have a roof over their heads by staying in some one's home (sofa surfing).

When I squat I find a place and I go in and I turn it into a home…if friends come around who hadn't been there before, believe me they think that I'm paying rent there and that's my proper living. Cause I find things on the road proper things…it's amazing what people throw out…TV, high-fi system systems, brand new mattress, wardrobes…good carpets and that. I furnish the whole squat and it looks like a home (P7)

Both the earlier properties of cycling and strategy relate to divergency, but the latter appears to be more strongly allied to it. Individuals become used to this existence, however unpleasant. In other words, the condition of divergency forces the individual to accept their way of living and this compounds their difficulties.

...eventually you work your way down [street homeless], eventually end up on the street. You do become use to it very quickly, a way of life, and it becomes difficult to get outta…it's just something you get use too (P6)

Despite their divergency, the individuals desire normality; while recognising the difficulties of establishing normality, there remains a strong need to have a 'normal life'. Some express the desire for a home that they can call their own, while others crave the social unit of a family, a job or genuine friendships. Some individuals have a wish to rekindle old family ties with their children. In essence, their desire for normality is about the individual wanting parts of a better life while zoning.

The hardest thing is living a normal life. I've always wanted to live a normal life, to get a job, be normal like everybody else…I know I would never get that, I don't think I would, that crosses my mind so often…that's what I would really like to achieve, a normal life…a job, a place, that's normal…It would mean a lot; it would mean I'm like everybody else, I'm not different from everybody else…normal persons gonna come in, go home, put their legs up, cook dinner, everything normal…I don't get that sort of life, that's not in my life at all… I'd just like my life to be better…maybe one day it will and maybe one day it won't…(P2)

...all that I want to get my life in track in order to just to see them [his children]…To find out where my son is, and start getting back a relationship with him. Cause he hasn't seen his dad for all them years, and probably forgotten me (P7)

However, within the conceptual ordering of zoning, there is a fundamental contradiction that clashes with their vision for normality. The contradiction is that when explored further, the individual who is zoning, does not actually wish to leave their state of zoning-out. They do not express a time frame to leave the world of zoning. The desire for normality merely becomes a passing thought, but not a reality.

An important element with the individual remaining in a state of zoning-out is the simple enjoyment of zoning, which comes from the substance use or the 'free lifestyle' of homeless life.

> *I don't want a time frame for anything; I think it's because of my bad habits which I enjoy doing and that's what delayed me partly (P2)*

The issue of social stigma is probably the most important element within the concept of divergency. Being homeless was associated with a great deal of stigma from a number of sources. Stigma was linked to people's perception of the homeless, for instance, the idea that homeless people are lazy and refuse to work, or the fear that people have that a homeless person will steal from them to finance their drug addiction.

> *When you're on the street people telling you to get a job, but how you meant to get a job when you don't have an address? how do your employer tell you that you've got a job and than it's just so much more to it then get a job and you'll be ok…I just use to say well you just give me one than. Ah if they do stop, ill explain it to them that it's not that simple as that I mean I have worked when I've been homeless, but you finish a days work and than if you've got nowhere to go, you might be awake all night and you go into work it would be the second day, you have a sleep, the whole day you're exhausted and you just cant, you can't do it. When you're homeless you can't organise a timetable for anything (P6)*

> *I just felt like a parasite…people were too scared to come near me…I've had that before. I've had that kind of thing off people before, I use to live on the streets, I use to look like a tramp and stuff (P1)*

The problem of stigma encountered by participants was emotionally devastating. It is important to note that individuals also felt stigma from institutions. This form of

stigmatisation came from a number of professionals, including the police force, probation service and health professionals. Individuals in this study felt that stereotyping affected the services available to them and that such stereotypes contributed to the stigma and social exclusion of these individuals. The reason for stigmatisation can also be due to their conceived substance misuse, their poor mental health and physical health, as in TB.

> *Anytime there is trouble the police are more likely to get the view the homeless person started it…Again it's just something you get use to (P6)*

> *…with my probation officer I was surprised. I went to shake his hand to say good-bye and he wouldn't shake my hand, because he thought he might catch something…I was bloody angry. I really was. You think I'm like a leper or something? (P4)*

> *It's just hard to explain its jus their attitude towards me [hospital staff] just cause they use to, like put the mask over their face, be scared to touch me and things like that. I can pick up on things like that it's not in my imagination, I'm not being paranoid I know they were paranoid about even taking my temperature, it really showed (P1).*

Stigma can be clearly found within the homeless world, but particularly when individuals approached service providers. Although participants in this study had the same rights to services as everyone else, prejudice against them was often felt which prevented them accessing important services, such as basic health care. This stigma is clearly observed in many of the narrated experiences of participants in this study. Below is a quote to highlight one poignant example of an individual's experience:

> *…one day I collapsed in the street, and someone phoned an ambulance. I went to the hospital. But as soon as the doctor heard I was a heroin addict they never even examined me…he seemed convinced that I was only there to try and*

get drugs out of him…he told me I was constipated…and sent me back to the hostel, couldn't get out of my bed, for two weeks…I couldn't eat. I was sent back to the hospital… we found out my kidneys were failing and I had TB in my spine and in my lungs. I had thrush all through my stomach, my throat, and an abscess in my spine, my kidneys were only working one percent, my legs and my feet ended up swelling up, because of proteins that were leaving out my kidneys… I knew there was something not right that day, I mean I know the side effects of drugs…they asked me why I didn't come in sooner? I said I was here but you sent me home but they reckon I got in just in time (TB)…when you are homeless, especially if you've got a heroin habit as well, if you go into hospital there's assumptions, a lot of doctors do think that you're just there to get drugs. I mean whether they're right or wrong, it's like assumption of types… (P6)

Individuals themselves, however, also neglect signs of ill health and TB attributing these symptoms to zoning-out activities such as substance use, or because of their lifestyles.

I know I'm not looking after myself enough. Sometimes I feel rough and down like…most of the time I feel rough… run out, drained (P2)

look at me I'm really knackered and I can't eat nothing. My health, my health is not doing well (P10)

Furthermore, the majority of participants explained how negative the zoning-out experience is, affecting their ability to attend clinic for their TB treatment. The main concern for individuals zoning-out does not appear to be taking their TB medication. This is because other more immediate needs have to be met. Almost all the individuals who were zoning-out, had at least one form of substance addiction that impacted adherence to their TB treatment.

...I kept missing it a few times and stuff like that [TB meds] ... (P4)

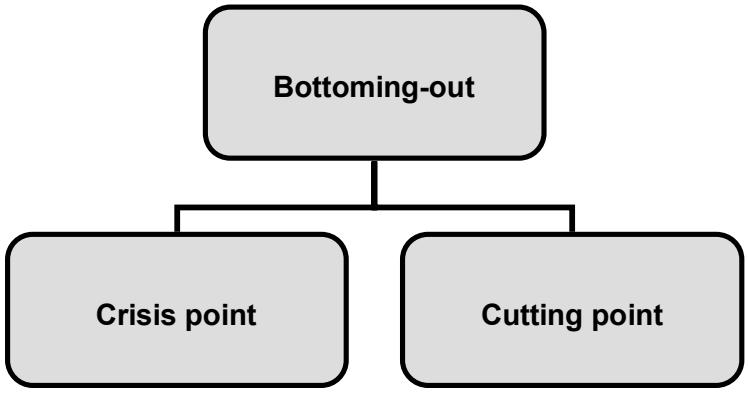
I did have other issues as well apart from the TB [drug & alcohol issues]...sometimes it's difficult, I mean I'm an ex-user, cause I'm coming off a lot of other stuff as well...so my heads kinda all over the place...there are times were it's kinda difficult to get ere (TB clinic)...it was a multiple habit it wasn't just a heroin habit, It was a heroin, crack cocaine, and alcohol habit... (P1)

I'm not good at taking my tablets sometimes. I didn't even come up on Monday [clinic]. I don't know why, I'm smoking drugs and drinking and I don't care about myself enough to come... it's not gonna hurt not to take the tablet or miss one day. I don't feel it's gonna do any harm...that's my reason I have to make a reason up that's my reason because I'm enjoying myself (P2)

5.4 Properties of Bottoming-out

Bottoming-out has two important properties: crisis point and cutting point (see Figure 6). While TB is of little concern to homeless people during the zoning-out stage, it forms an important factor in moving the individual out of zoning.

Figure 6: Bottoming-out



5.4.1 The Conditions of Crisis point

The experience of bottoming-out is triggered by a crisis. With almost all of the participants, it was hospitalisation or the diagnosis of TB that initiated the individual's transition from zoning-out to bottoming-out. It was this life/death fear that triggered the sense of shock out of zoning.

> *I was really ill and to start with, I didn't know what was wrong I didn't know any idea what TB was…I thought I could die from it [TB]… I had no clue about it and when I heard I had TB…I thought I had to have an operation for my lungs… and that's a risk and you can die, I thought I would stop breathing and be on a support machine and I may not come round…all sort of things were going through my mind…cause I didn't understand anything about TB…(P2)*

This crisis awakens the individual from a state of zoning, the experience brings them to an all-time low. The use of substances as a coping method does not rescue the individual from bottoming. Emotionally the individual is depressed and experiences rock-bottom phenomena. At this stage they could not feel any lower.

> *I've been homeless in the past, but it's been the only time I've been homeless with TB… (P1)*

> *some doctor told me I have TB…nightmare… months I am sad, I am cry not in the eye my heart cry (P9)*

> *I think I was going through depression, which only made it worst, I think it went to the point where it got too much…(P5)*

…I got sectioned for five days, because this TB was just starting to freak me out…I don't know it's hard for me, it's hard for me. I wish I'd just died in the hospital (P10)

The traumatic event of the diagnosis of TB propels the individual into a state of fear, fear of the side effects of treatment, fear of the stigma, fear of hospitalisation and the genuine fear of the unknown. Furthermore, a number of individuals were not diagnosed until the disease was at an advanced stage, so they were in a more critical state.

I was told it was TB and it was quite advanced stage as well. I had I had lost a lot of weight… apparently I was quite ill, but it was defined as extensive TB, the TB…What I know about it, is that it can kill you (P5)

…when I came out of intensive care I couldn't even sit up on the bed, for six weeks I was totally, totally wounded-up basically… I didn't realise it could affect other parts of your body as well…I didn't know anything about the treatment on offer or how long it was going to take, until I was in the hospital (P6)

As most of the individuals did not realise that they had TB, they considered their symptoms were due to their zoning life style and the diagnosis came as a shock.

I didn't know nothing about TB, until I got it. I thought I had a bad chest, cause I was purring…I didn't realise he was taking me to the TB clinic. They said you've got TB mate and you've got to start treatment right now (P4)

…I hadn't been to see a doctor for about ten years and I thought it was just side effects of the heroin or whatever. And I didn't realise I was ill [TB]... Like I never knew I was ill till I collapsed (P6)

I thought it was like pneumonia or something like that. I took no notice of it I was just coughing and bring it up…I was in the ward [hospital]… when they found that it was TB I had. And that was a shock… (P7)

…I didn't think even it was TB, because I was thinking it was because I was drinking too much or smoking drugs and things that made me sick…you know I didn't even think it could be TB (P13)

Fear of the unknown triggers deep feelings of despair, and awareness of their vulnerability and mortality. Intense feelings begin to germinate about their lives and the meaning of this experience.

I had no clue…I was really scared, and thought I was going to die or, felt alarmed and there's no one there beside me, so I was really in deep thoughts…I was scared and I feel alone…(P2)

When individuals realise the seriousness of their TB condition and how long the treatment regime is to last, they are again anxious, especially when they discover they have drug resistance[16], which requires treatment for 18 or more months. One individual in particular felt that the diagnosis of TB was a personal punishment of some kind. It is clear that the impact of the diagnosis is fundamentally related to the fear that the individual has of not surviving this event.

…I remember her saying, [key worker] well if it is TB it's going to be a minimum of six months [treatment], and I thought that was long…I was told that I had extensive TB and that the TB I had is resistant, so therefore my TB therapy would be 18 months instead of 6 months or a year [doctors]. Then I was told it may go on to two years…I was really getting pissed off. I was really depressed. I remember I was really down, it was just like a knock, I don't know I lost something, I couldn't think why I reacted like that, but I just didn't like

[16] See Chapter Two for information on drug resistance.

the idea of taking all the medication. When she told me 18 months like for goodness sake this is hopeless. You know, six months yeah, but 18, wow (P5)

I'm scared…It makes me feel miserable. Makes me feel as if I I'm being punished for something that I've done, I don't know what I've done…To start with I didn't really know much about it (TB)…when they started putting masks and that on your face, I never thought I would survive that (P10)

Not only is it the knowledge of having TB that impacts as a crisis point in bottoming-out, it is the physical side effects and fear of its manifestation. For instance, the side effects attributed to taking TB medication such as vomiting, increases the individual's level of fear. It is this added emotional influence that can have a bearing on the individual and cause them for example to cease drinking. The individual learns that alcohol cessation eliminates vomiting.

Fear is a multivariable element in the bottoming-out process, coming from various sources, which include fear of the side effects of TB treatment and is an important aspect of Survivalising.

Sometimes I use to get scared coming and taking the medication because I thought cause I use to vomit a lot when I use to take it…It's difficult, I mean there was a time when I was being very very sick and I use to dread I knew I can't take it, but it use to fill me with fear, of being sick… (P1)

The authority structure of a hospital has been both a negative and positive experience for the individuals, but for the majority it was negative. Hospitalisation was seen as a 'lock-up' situation, similar to a prison environment, in which the individual had little or no control over their fate. Being removed from the familiar surroundings of the outside zoning-world was described as a catastrophic event. While being placed in an isolation room for infection control purposes, brought about feelings that the

individual was dirty or should be removed from contact with other people, which increased the individual's sense of loneliness and despair.

> *...It was horrible. I felt like a really dirty person, I felt like what's wrong with me? It really freaked me out to be honest. It really freaked me out… the nurses over on the ward I don't think they really did understand. They did kinda treat me like a bit of a germ…I hated it over there [hospital]… (P1)*

> *Well, I've never ever been into hospital before, so that was an experience. I had my own room because I was contagious at the time…I didn't like it…I realised how ill I was and it was like being locked up. I had to stay in my room, it was horrible, you have to lie in bed all day, all the time (P5)*

Having TB was associated with a great deal of stigma, seen as an embarrassing condition. Although common among the homeless, it was rarely discussed, as it brought about feelings of shock and anxiety.

Individuals described the stigma they encountered from other homeless people. The negative reactions from them often left individuals feeling they wished they had not disclosed their TB status. Some that found out about the TB in others would further stigmatise the individual by detaching themselves from the individual who was already isolated, while others separated themselves for physical fear of the 'contagious' nature of the disease.

> *It's a disease not no one really talks about [TB/homeless people] (P6)*

> *I'd rather wish I didn't have TB. I don't like people to know I've got TB... embarrassing… they tend to say "you got TB burn the bottle [crack pipe] before you finished, you can't share a can no, a pipe or anything, you can't…*

they gotta keep reminding me that I've got TB and that really upsets me, that really does up set me. I mean I know that I've got TB... (P2)

One of my friends came to visit me [in hospital]… I felt a bit cast out like. Like they were classing me as somebody different, or somebody they didn't even want to associate with. I appealed to them that it's been covered now (P7)

Individuals who were admitted to hospital due to their TB described the symbolic phenomenon of 'masking'. Using a mask was an important element of infection control, which affected the stigmatisation of these individuals. The simple act of putting on a mask would trigger a strong fear of the individual suffering from TB. 'Masking' therefore further isolated the individual so visitors were too afraid to visit the homeless person in hospital.

When they started putting masks and that on your face, I never thought I would survive that…I wasn't allowed out of the hospital. I wasn't allowed to mix with people. I wasn't even allowed to get a cigarette, until I had that mask on…you're walking about the hospital and people would be looking at you thinking what's wrong with him? Why's he got to wear a mask?... the visitors and that have got to wear masks. It's bizarre; it makes you feel as though you have got the plague. You just think well fuck them, I'm only in here to get better [hospital] their thinking, look at you something wrong with you. I'm in here to get better (P10)

The other stigmatising element of TB is that of the actual bacterial nature of the condition itself. The notion of the 'germ' was personified by the individual and associated with being a dirty, diseased person. The symbolic nature of the TB 'germ' further exacerbates the stigma felt by the individual.

... people were too scared to come near me…I think people see it as a dirty thing…they see, that only dirty people get that [TB]…it's the kind of feeling I get from it… (P1)

...someone said 'look at him he looks really ill, he's sick"' and they said 'go away go away, move, move, move'… somebody even said it must be TB or something, and someone else said 'go back to the hospital, go back to the hospital'…it was obviously not a nice experience, but I just had to cope with it because I was rejected, it's quite unfair… (P5)

The stigma felt by individuals not only came from the reactions of friends, but also from family members. TB can be so stigmatising that individuals are actually made homeless. One individual in the study was so stigmatised by work colleagues that he lost his job and his accommodation, which was part of this work package; thus the individual became jobless and homeless in one fell swoop. Another individual lost his job, because he was unable to work because of the stigma of TB. A third individual felt the stigma so much that he slept rough because he was unable to stay at his sister's house.

Just I want a new life…I become homeless because I become sick (TB). I lost my job; I lost my rent, I'm not like that (P8)

...after I came out of the hospital…they were saying I can't really go back to the house because of TB, I couldn't go back to my sister's so I got some blankets and went to a stairs and sleep (P7)

Surprisingly the stigma felt by individuals was not limited to that from other homeless people, but also from professionals such as a probation officer.

...I'm quite open about it (TB). I don't lie to anybody, they all know like that I've got TB. I don't think it's anything to be embarrassed about. And no one has ever um, apart from my probation officer once. I was surprised. I went to shake his hand to say good-bye and he wouldn't shake my hand, because he thought he might catch something yeah (P4)

It became clear that if individuals had problems with health professionals, particularly when they had bottomed-out and stigmatisation became apparent, not only did they feel a further drop in their self-esteem, they were also likely to return to zoning activities as opposed to moving into self-realisation.

Although the majority of participants had experienced bottoming-out, a small number were able to move directly from zoning-out to self-realisation[17]. This was attributed to support on diagnosis from health professionals, appropriate care delivery and importantly the rapport with staff and a lack of stigmatisation.

Individuals who had bottomed-out described effective face-to-face interaction with health professionals and how a positive hospital experience enabled them to increase their understanding of TB. With the increase in health education and their knowledge base, individuals felt empowered. Positive relationships with health professionals increased the individual's self-esteem and became an important factor in their adherence to TB treatment.

Positive interaction caused individuals to trust in others, something that previously was lacking in their social world. Although TB was seen by all the individuals as a negative, this new knowledge enabled them to move away from stigmatisation of TB and gain a sense of empowerment to address feelings of despair and stigma. The positive face-to-face interaction is thus vital in de-stigmatisation and increases the individual's sense of 'normality'. A strategy of good health professional communication and health education not only increases self-esteem but also

[17] As illustrated in Figure 9 on page 187.

increases the potential of adherence to treatment. Those that described the hospital experience as positive were more likely to move towards self-realisation and healing.

5.4.2 The Conditions of Cutting-point

A possible threat to the individual's survival brings about the condition of a *cutting-point* or critical juncture in the person's experience: it is the individual's conscious alarm in a state of total despair. As described earlier, the individual is forced to halt or reduce their zoning activities.

Although it is a tremendously intense and frightening experience for the individual, the cutting-point can provide the motivation to change their lives for the better. It is this moment, in which their perception of their world has fundamentally changed, which provides the individual with the opportunity to heal.

Cutting point, enables the individual to transfer from the state of bottoming-out into another state. This condition places the individual at a crossroad and forms a catalyst to change, as they acknowledge that they have had exhausted the possibilities of zoning-out. A conscious awareness develops of their inability to cope at a satisfactory level. It is at the cutting-point that the real shock of what has occurred (TB diagnosis) becomes a 'wake-up call'. The personal catastrophic event of diagnosis and fear projects the individual into a sense of awakening. It is what can be described as a 'life-flashing before their eyes' phenomenon.

> *When the man [doctor] said the brain scan, all I thought, when he said about my brain I just thought it was all over. This is it (P11)*

> *...I done very well in this situation [hospital], because when I was in there for the 19 days I didn't smoke one cigarette, and I didn't have any crack in my system. When I thought that well if I can do that, for 19 days, I can stop*

smoking this thing. The only thing that really made me think I can stop and get out of this drug scene… (P7)

A bit frightened at first because I heard TB you can die from…I got a bit more frightened…I stopped taking my drugs (P4)

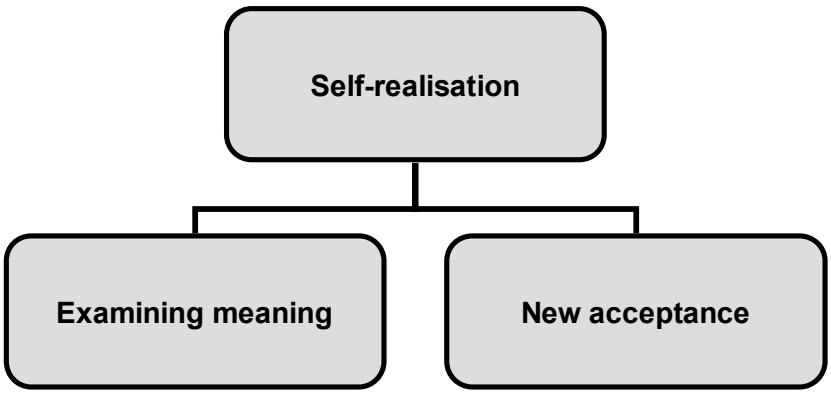
When I went into hospital I cut myself down [heroin]…going into hospital I didn't have a choice. I couldn't go out there and manage [heroin habit] because I couldn't stand up never mind walk. So I had to go on methadone, so I went on to that and that's when my priorities changed, being on methadone won't kill me, whereas the other things would so I had to get the TB sorted out, get my kidneys sorted out, and then sometime in the future I can worry about coming off the methadone (P6)

The acute setting of the hospital was the environment where most individuals discovered they had TB. In these acute settings, individuals recognised the life threatening risk of having TB. It is this life or death fear that lifts them out of zoning-out.

5.5 Properties of Self-realisation

Self-realisation encompasses two important properties, examining meaning and new acceptance (see Figure 7). When an individual moves from bottoming-out they hit the state of self-realisation, which can be described as a self-enlightenment or awakening, which occurs through deliberation and self-reflection. It is only through this awakening that the individual's feelings become self-knowledge; through the receiving of self-realisation, life becomes meaningful and they begin to radiate their sense of value, newfound wishes and life goals. Individuals who are self-realising recognise that they are on a new and important path towards healing.

Figure 7: Self-realisation



During self-realisation, the individual's life suddenly becomes clear and they realise that they have a new beginning. They are no longer who they were before and realise that zoning-out is not what lies ahead of them, recognising this was a state of discontent and indifference.

> *I just had enough… I think I had learnt enough, I had seen enough and I'd done enough I didn't want to be out there anymore. I wanted to go home at night, instead of having to look for a bed to sleep on (P3)*

Once bottomed-out, a psychological change forms within the individual, in which they become aware of the need to move away from zoning. With this comes a new desire for change. This phenomenon can be described as a moment of clarity or a sense of eureka. Re-socialisation becomes a key factor during this period and in the later stage of healing (see Section 5.6.3). Self-realisation is a state that cannot be learned from another, but is self-experienced. It is an ineffable and un-teachable phenomenon.

> *…Sick of waking up sick every morning, with waking up withdrawing every morning and having to go out shoplifting every single day of my life, just to feel well [for drugs]. It's like walking around with a monkey on your back all the time, y'know what I mean, just sick of it, sick of going to prison, sick of getting*

arrested, sick of the whole lot…I just wanted to be stabilised, so that's what I did, I went to xxxxxxxx house and said I can't handle this, plus I had a alcohol problem, so it was a multiple habit it wasn't just a heroin habit. It was a heroin, crack cocaine, and alcohol habit, and I couldn't keep up with it, cause I would have to earn like two hundred pound a day, at the time, to be able to satisfy, or keep myself feeling normal (P4)

…it made me stop and think… at first like I would have to go off the heroin (P6)

…just the struggle to maintain a heroin addict. The anxiety, the struggle. And just to give it a break…just the frustration, and the need to have to go out and look for the money, just to make it my habit, it's crazy. It would be freezing cold and I'd go out there to do it. That's why I think I got lost, lost in the street as well, because of the heroin habit (P5)

Although health professionals can mobilise their efforts and assist homeless individuals at any stage of Survivalising, it is at this stage where it is crucial and they have the most significant influence on whether the individuals move forward to the next important phase of healing. However, if individuals are stigmatised and do not receive appropriate treatment by health professionals they are at risk of losing their dignity and falling back into zoning activities.

When health professionals engage in good communication and show respect to homeless individuals they cultivate positive relationships[18] that encourage the individual to reach the desired state of healing. This can only occur when health professionals show a genuine and sincere care for the vulnerable individual. Self-realisation is important because the individual looks at their future rather than being immersed in the everyday cycle of the homeless existence.

[18] See Section 6.3.3 for Simmons (1993) study on cultivating relationships.

5.5.1 The Conditions of Examining Meaning

Examining meaning is an important property for the individual who is in the process of self-realisation. It is the individual examining a new meaning for their life. Perhaps for the first time in a long while, the individual's life means a considerable amount to them. In other words, experiencing the fear of 'almost' losing it from TB brings value. It was the 'life flashing' phenomenon of bottoming-out that enabled them to propel into self-realisation. The risk of death makes them see their lives in a new light, where things that are more important become apparent to them.

> *...when I came here [hospital] with TB they give me three weeks to live, and it really freaked me out, I mean I got a second chance, so I have to try and do it properly this time (P3)*

The circle of events that have led them to self-realise become clear in their minds. In addition, they realise the previous path would not meet their current agenda of change and new philosophical outlook. Through the realisation of shock and fear that came from bottoming-out, individuals feel lucky to be alive. For some, the agenda for positive change comes from their new desire to rekindle family links, which provides them with new meaning in their lives. For others, it is about getting better and the meaning comes from having a second chance in life. The 'wake-up' call enabled them to put their life into perspective.

Examining this new meaning also brings about new concerns, unprecedented to those previously expressed, which were related to zoning. These new concerns are about themselves, but also about others such as the family unit. Individuals now realise the impact of their actions on family and realise the importance of regaining and maintaining a 'normal' life.

> *A lot of things happened to me when I was on the streets. I came close to death so many times, I was getting beaten-up by people, I got kidnapped, I had a gun held to my head and I jus had enough I was visiting my daughter more often*

and I wanted to be closer to her. I wanted to live somewhere and do something, so that's it really (P3)

This is it. This is my wake up call [TB]. Like you know, I got to fix-up, this is do or die like. Its time to sort my shit out. I'm getting too old for this now. I'm forty years old and for the last couple of years. I ain't even seen my kid" (P11)

...for the first time in my life, my life meant something to me ...I haven't done enough in my life. I haven't seen by daughter or my family enough, all these sort of things were going through my mind... (P2)

Examining new meaning is also focused on their desire to leave their homeless world by engaging with people and gaining housing, so they can have their own space and security to cater for their new needs.

But I end up going in hospital and they say everything for a reason, maybe I needed this TB to get the start I needed, so that I can get a flat. Cause this, bed-sit is a start to getting a flat inat... (P11)

Previously individuals were concerned with numbing themselves from their daily adversities, while now they need to actually feel their world through examining what they want in life. It is an important move away from trying to cope with their conditions to realising their importance in life, and making their own conditions. When individuals examine what they want and what is now important to them, they realise change is possible and they have a second chance to another life.

It's a bad thing to say but I think I needed this [TB]. ...the whole experience was something else, but I think that I needed it for me to realise that I'm taking life for granted and as far as I'm concerned, this is my last chance to sort my shit out and get it together. I'm doing it for number one, I've got to do if for

myself, because if I'm no good to myself, I'm no good to my kids. I needed something like this to happen to me, to give me that wake-up call to say its time to fix-up your life and sort your shit-up…(P11)

5.5.2 The Conditions of New Acceptance

Once individuals have examined themselves, they are able to benefit from their new philosophy by accepting this new realisation. It is at this stage that they are self aware of their need to accept help. Individuals who are at this stage of self-realisation look at their lives retrospectively and realise that the cycling, strategy and diverging that were part of zoning-out was not benefiting them.

I had enough of it, and I put my hands out, I need help, and that's when I went back to the primary care unit and said, look, I need some help. And then they put me on the methadone program, and stabilised me and it means me not to go out shoplifting anymore, it keeps me out of trouble, so I don't have to go shoplifting, keeps me out of prison, just got the alcohol to deal with now (P4)

Over time, individuals realise the benefits of ceasing or reducing their zoning activities. Those who begin to stop with many of the zoning activities begin to accept the benefits to their health, because they see the actual results, such as the sickness or vomiting ceasing. This clear evidence provides them with further impetus for self-change, while previously they were unable to experience the benefits of stopping zoning. A new sense of responsibility becomes apparent.

...I've been sober for nine days now and my sickness has stopped (P1)

I'm not as worried or anxious now because these people here are very good, they're very very good. Um that doctor xxxxxx he's one of the best, I think and I'm quite happy with the prognosis or diagnosis or what ever you want to call it. And like I said I don't feel half as bad as what I did a year ago (P4)

I didn't want to face my responsibility, was trying to get high to get away from everything. But it doesn't work because you still have to come back to reality. No matter how much you smoke [crack], once you sober up or get real, then you still have to come back to reality… (P11)

This newfound self-knowledge gained through their experience, enables the individual to realise the importance of TB treatment. Individuals begin to make a concerted effort to adhere to TB treatment. They realise that their life styles need to be conducive to maintaining good health, and making improvements to other areas of their lives, such as attending clinics.

This new acceptance acknowledges the seriousness of TB, but more importantly, it is the realisation that they themselves are the only ones who can take the important steps to change and they accept that they are, indeed, able to change. Although it is the individual themselves who must self-realise, the importance of health professionals working with them is paramount in increasing their TB knowledge and assisting individuals to adhere to treatment.

I'm on treatment to make me better, and I'm gonna get better (P1)

…they were really on the ball about making sure I did take TB meds (adhering TB meds). Like they phoning through to my place, the DDU (drug dependency unit) and primary care unit, making sure that I take my tablets in front of the doctor (DOT) and signed and all that and it dawned on me the seriousness of it…you could die if you don't take your tablets basically, but I didn't really realise it before. It's only when you get something, isn't it and than you realise the seriousness of it. I didn't realise that…I feel this treatment that I'm on is very important. I didn't realise at first quite how important it was. I kept missing it a few times and stuff like that, but I realise now, I was told your body can get resistant to the tablets if you don't take them (P4)

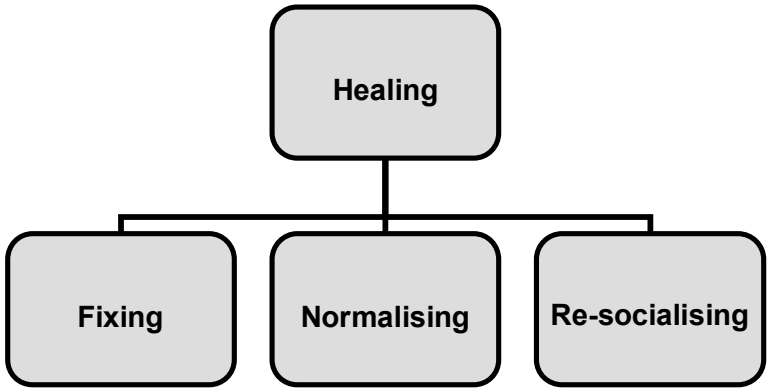
I'm scared of hospitals, usually, I'm surprised that I never even done a runner out there, because I hate hospitals, but I know that I had to do it, otherwise I'd be just killing myself wouldn't I really? I had to go through the treatment (P11)

5.6 Properties of Healing

The homeless individuals conceptual ordering at the stage of healing clearly alters when compared to earlier phases of Survivalising, particularly with previous zoning activities. For instance, many individuals who are healing adhere to TB treatment, apply for housing and attend drug dependency units for their substance addictions. These new conceptual orders become a high priority.

Healing is both a new attitude to their lives, but also a fundamental change in their behaviour. Individuals make important choices and it is about a method of getting around and living in their new world through re-socialisation. The state of healing allows the individual to move on to a new place in their lives. Healing encompasses a number of significant properties, including fixing, normalising and re-socialising (see Figure 8).

Figure 8: Healing



5.6.1 The Conditions of Fixing

Fixing is about the individual improving and self-progressing. Once the individual has realised that their health can and is improving, their standard of life is enhanced, they then put their efforts into areas that need 'fixing' or mending.

Individuals become active participants in healing, whether it is in the area of housing, health, employment or family relationships. They pay attention to their needs and address issues in their lives that they previously ignored. Individuals are now able to see clear improvements in all areas. This acts as a further incentive to continue 'fixing' and actions and activities are focused on further progression.

When previously their focus and concern was on zoning-out, individuals now concentrate their efforts on healing and dealing with their problems. Individuals realise that fixing takes time and they appreciate that much effort is needed on their part. They acknowledge it is about making themselves better through concentrated effort and hard work.

> *Every time I come here they're showing me x-rays and I can see that my lungs are getting clearer…I'm feeling a lot better now, than I was three months ago…Before I knew I was ill, the main thing I was worried about was getting off the heroin, but now I'm on the methadone. I'm quite happy just to keep taking it and concentrating on the other things. I mean I would much rather be in a flat of my own but, I know it's going to take time and I'm quite happy as long as I'm in the hostel. I know I'm getting slowly better as long as I keep doing that… (P6)*

Furthermore, the fruits of their efforts become quickly apparent. For instance, with their efforts in gaining housing, individuals realise that they have less adversity by not having to move from place to place, searching for shelter and safety. Those who are healing, attempt to 'fix' relationships that were once lost through zoning and find that once established again, the relationships become important elements in their

lives and in their healing process. Their new sense of responsibility to other people becomes significant and they see themselves as important factors in the lives of other people as well.

> *I better do what I can and just be there for me and my kids. I miss my kids so much. I just want to be there for them (P11)*

> *My health and everything has improved… it's like the standard of my life... I start eating better and being more active, being more engaged, the most important thing now is just improving. I'm waiting for a council flat, and I've started my career a little bit, cause I was a trained actor before. I've done some performances last year, and I'm just trying to build that up…Mine definitely was from living on the streets (TB), from the lifestyle, from using drugs and not eating regular, not sleeping, like I'd be up for three or four days at a time, and it just got worse, and I just needed to sort it out. And I could see how it happened, and I could see how I got better as well… I started cooking again, y'know that's how I became known as a cook there (hostel). I started improving straight away, once I paid attention to it (P5)*

Adherence to TB treatment becomes a high priority. Individuals adhere to treatment and this becomes a vital part of re-assembling their lives. Individuals realise that completing treatment does cure them of TB and makes them feel better.

> *Our goal now is to finish the TB treatment (P11)*

> *Because I have TB, I've been coming quite regular for check-ups, because my TB was extensive, so it was quite advanced…At the beginning, I had a hard time taking my medication, I had to take 17 tablets all in all, it was like three times a week, but now I'm down to six or seven tablets, which is on a regular basis (P5)*

What is more, they see the importance and value of other healing as in drug rehabilitation, which has an important bearing on fixing areas of themselves that were de-constructed from zoning-out.

> *...getting my treatment is the most important thing to me. I mean, I'm not just on treatment for TB I'm on treatment like I say for other things (heroin dependence-methadone). It's very important for me to get treatment because I'm trying to sort my life out now (P1)*

With fixing, comes a new world of social interaction, where individuals develop social support networks that instigate meaningful relationships. The networks are linked to their healing agenda such as drug dependency units (DDU).

Adherence becomes a new priority within the healing process and individuals maintain close links to these networks, which in turn, promote re-socialisation and further normalisation. The social interaction that comes about from the individual's desire to fix, increases their sense of self-worth and, thus, confidence. The process of fixing is about the individual becoming a new person and increases their sense of well-being, promoting their self-identity.

Some individuals begin to change direction and transfer their living circumstances from street life (rough sleeping) to hostel life, while others apply for housing. Relationship formulation is attributed to the individual acquiring a sense of identity. Social support networks are important influences in assisting individuals to transform and fix their lives.

With the increase in treatment knowledge, individuals are able to break the self-stigma they may hold about TB. Good adherence becomes meaningful - increasing their sense of self-worth - and they find they are in more control of their lives. TB treatment provides individuals with a positive focus. Actually adhering to their treatment regimes enables them to feel in control of their healing process and

increases their self-esteem, making the individual feel empowered to 'treat themselves' and improve their health, through their own actions of adherence. What is more, this new focus provides them with a new 'busy' activity, replacing old zoning activities which before kept them cycling and strategising further diverging them away from their sense of 'normality'.

> *...our goal now is to, well I got to, and I want to finish this treatment, the TB treatment and finally get off the methadone and that, and stop taking drugs all together. And to be there for my kids (P11)*

> *...makes me feel like I do something with myself, with my health, I care about my health and I've achieved I've managed to come up and at least care about myself enough to get my medication for myself to get myself better when I don't do nothing I don't feel really good about myself (P2)*

> *that's like giving me something to do for the three days of the week that I know I should (take TB treatment)...I've got something to focus on, which is good, like coming here three day's a week, it's giving me something to do (P7)*

5.6.2 The Conditions of Normalising

The second property of healing is normalising. Due to the new state of healing, individuals recognise that the degree of adversity is considerably less during this phase of Survivalising. Individuals find themselves having a better quality of life and their basic standard of living is much improved due to their efforts of 'fixing'. Consequently a new conceptual ordering of their lives is constructed, such as receiving treatment for TB and substance use, and finding housing. This clear change in attitude and priorities is triggered by the individual's desire for normality.

> *I've just got to better my life...now I've got a roof over my head. Its mine maybe only a room, but its mine and I've got somewhere I can go every night.*

It's nice, it's warm, and I got my telly, that's all I need. I've got a fridge in there, telly, wardrobe where my clothes go. I don't need more then that right now (P11)

With 'normalising' the individual develops hopes of changing their lives into a more 'normal' existence. They take concerted steps to make this desire a reality, by prioritising their needs and by taking rigorous steps towards achieving these goals.

"I'm on treatment for drugs; I'm on treatment for alcohol. I go to groups and that, at the moment it just sorting out my health, that is my priority at the moment, and then I can think about other things once I'm, once I'm better…I live in a hostel. It's a little hostel place, but I should hopefully get housed soon, …At the moment, it's the only thing I'm concentrating on, I've got so much work to do, recovering from drugs and alcohol as well, it does take-up most of my time. I mean once I've had all the treatment and everything, then I can pursue other things, but at the moment it what I'm gonna do, I'm gonna get myself better" (P1)

With the change in priorities, individuals are kept occupied in attending to 'normalising' activities. It is interesting to note that there is a fundamental change in their psychological construct of other homeless people who are zoning. This can be observed when the individual who is healing separates themselves from those that zone by expressing that those zoning make self-excuses. This psychological separation is part of the normalising phenomenon, which propels them away from those that they see as leading 'abnormal' lives towards what they see as 'normality'. Although they still recognise themselves as homeless they separate themselves to highlight their difference in their 'normalising'.

…obviously when you're drinking your medication not going to work properly, your medication doesn't work properly that means you're going to be on treatment for longer… it's bad that people are in that situation, but I mean

people don't really need to be in that situation anymore, I mean I got a little house, a hostel place, y'know?, I believe now, that if people are living on the streets, it because they wanna, because there's absolutely no reason for people to be on the street anymore, they're not allowed to live here on the street no more, it's against the law... (P1)

5.6.3 The Conditions of Re-socialisation

Out of the desire for normalising individuals immerse themselves in the process of re-socialisation. Normalisation is, therefore, a process of accepting the need for a 'normal' life, and re-socialisation helps them achieve it. When previously they found themselves unable to express themselves through 'socially accepted' means because of the zoning state, now re-socialisation becomes a reality. Re-socialisation enables the individual to communicate their needs and follow the process of healing by engaging with medical and social care providers.

before I wasn't so open. I wouldn't talk about my self, or nothing like this conversation we definitely wouldn't of had. No because I wasn't one for expressing myself…it's like the hospital that situation…it made me face reality and I've got to sort my shit-out and all this helps me expressing myself, well as before everything I would keep in which ain't a good thing. So I can only be bettering my self, that's what I'm still going to keep on doing (P11)

Help is willingly accepted and increased service support provides further re-socialisation. It is the interaction and support from social networks such as health professionals that increases re-socialisation. Social regime is also accepted and individuals continue their eagerness to learn more about their new world. As individuals develop networks and receive increased support, their desire to learn about healing grows. During this stage of Survivalising, individuals find that coping is easier and the adversities of survival are diminished.

...I'm trying to follow the process, and I do have this sort of support network. That's in the hostel as well as here [clinic], in that they've supported me

through my TB... just by being there, because I was seriously ill, and because of my situation I had just come off the street and that. I think they put in extra effort into me…it has become easier to deal with, because they facilitated the medication and when I first had TB they use to come to my hostel and bring my medication and like sit there and make me take it in front of them, but they're not so strict now because I've got use that, so I get the medication at the chemist now…I'm aware of what medication I'm taking and how I should be taking them. I'm always eager to know how I'm progressing and to learn… (P5)

With the result of coping more effectively in their social world, individuals discover their newfound independence. They find they are more adept at dealing with day-to-day issues and life for them is easier to manage. Instead of being in a vicious circle of zoning, the individual is facilitating their own Survivalising process through healing. However, with the increase in their sense of independence, comes individual responsibility. Increased re-socialisation means that the individual takes on new roles and responsibilities. Family and friends become priorities and individuals themselves are important in maintaining these positive relationships through the new responsibilities to these social units.

…with my kids and that, I've got access to my kids now, started talking to my kids like. I'm getting too old for this, for that drugs game, and I know that I've got responsibilities. And I want to watch my kids them grow, and them to have their kids (P11)

The social mobility that comes from re-socialisation also affects other elements in the individual's life, such as taking steps to get out of homelessness through applying for housing. With the change in social condition through re-socialisation, comes social mobility and thus feelings of higher self-esteem. This leads to a further change in their conceptual ordering which accounts for the response to improved adherence.

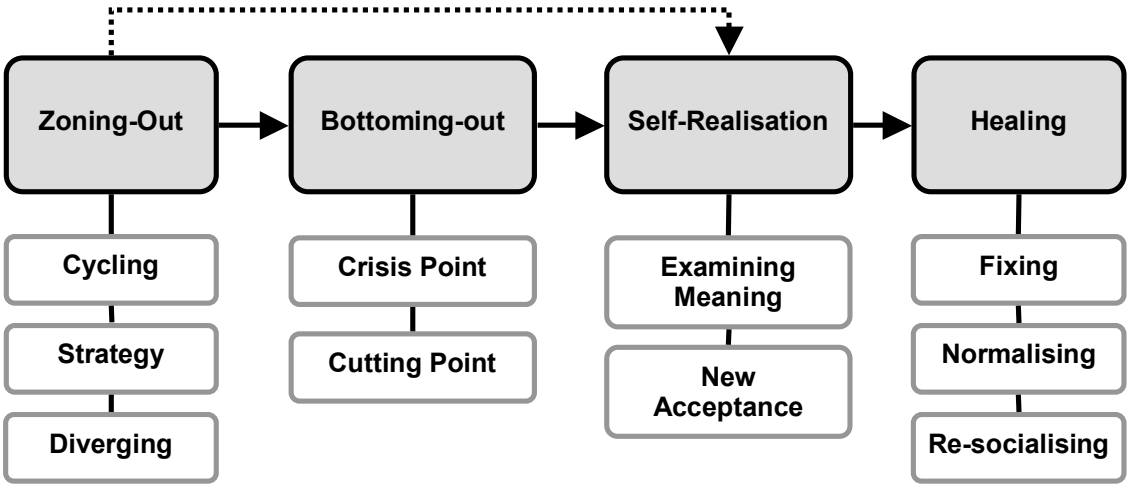
...obviously the medication I take, I got to take that... also chasing the staff up about trying to get me housed as well...these days I'm just trying to get my fitness back. I feel like my priorities have changed (P6)

5.7 Conclusion

This chapter has presented a Grounded Theory of Survivalising and identified it as a basic social process in which homeless people engage. The process of Survivalising includes four important phases: zoning-out, bottoming-out, self-realisation and healing. The theory was grounded in the experiences of homeless participants diagnosed with TB and influenced by the theoretical construct of the basic social processes as described by Glaser (1978).

The diagram below (Figure 9) shows how the properties are connected to the categories of Survivalising.

Figure 9: Social Process of Survivalising



Through an in-depth exploration of these individual's experiences, the researcher was able to address the following research question:

> What does having tuberculosis mean to homeless people and how does this impact their opportunities to complete treatment?

What became clear from the results of this substantive study was that more was emerging than the issue of TB. Although concern about TB was expressed in some of the findings, the participants' main concern was dealing with and managing their complex and harsh existence. Survivalising was found to be the pattern basic to the organisation of these individuals' social behaviour and provided a clear consensus of their holistic experiences, which was constant in the findings as their main concern.

The process of Survivalising begins when the individual is in the process of zoning-out and progresses through bottoming-out, self-realisation and healing. Zoning-out itself includes three important properties: cycling, strategy and divergency. These components of zoning-out account for much of the daily experiences participants describe to deal with daily adversities. Individuals often engage in substance use as a chemical comforter to cope with the fear, stigma, and harshness of environment. Thus personal health becomes a low priority within their conceptual ordering.

However, at some point, a major personal crisis may shift the individual into a new state. This is described as bottoming-out, and includes the properties of crisis-point and cutting point. For the majority of individuals the crisis point was being admitted to the hospital or the shock of the TB diagnosis. The individual is in a state of intense fear and emotional saturation. Consequently, they find themselves at a cutting-point or critical juncture where they can no longer view themselves or their previous existence in the same way. They have received a shocking but clear 'wake-up call' that can enable them to move towards self-realisation.

Once the majority of participants had bottomed-out they entered a new stage called self-realisation. It is important to note that self-realisation depends on the *self* and only they can self-realise, it is not something that can be forced on them. It is an internal process, which involves two important properties. The first is that of the individual examining meaning, whereby they consider the importance of their lives. The value of some fundamental things becomes apparent to them and a new way of looking at life brings about new concerns such as a desire for rekindling family links, which can give new meaning.

The second property involves a new acceptance and comes about once they have examined meaning in their life. Individuals become self-aware and acknowledge help available to them. They also realise the benefits of moving away or reducing zoning-out activities, and come to see the positive results of ceasing or reducing these activities, which provides further impetus for change. Once the individual has accepted this new realisation, they appreciate the importance of changing by adhering to TB treatment. Consequently individuals are able to move towards improving themselves at a holistic level and towards healing.

When individuals are at the stage of healing their conceptual ordering is fundamentally different from the earlier phases of Survivalising. Individuals' sense of priorities alters dramatically and concentrated efforts are made to improve their lives by tackling such things as housing and drug dependency issues. Healing is a change in attitude and behaviour and involves three properties. The first is fixing, whereby participants take active steps to sort out important areas that need improving. Regularly attending TB clinic appointments are examples. Fixing is focused upon improving and further progressing themselves and putting back their fractured sense of existence.

Fixing both leads to and can be triggered by the second property of normalising, whereby individuals develop a strong desire for a 'normal' existence. In normalising, individuals segregate themselves from those zoning-out and take rigorous steps toward achieving their goals to 'get better' and heal. The process of normalising keeps the individual occupied as they attend to their new priorities of healing. Finally, the desire for normalising comes from the phenomenon of re-socialisation. Re-socialisation is an important property of healing. It occurs through the individual engaging with service providers. Individuals discover that engagement with others provides them with support and a new means of Survivalising. They develop social networks, which assist their desire for healing, making it easier to cope. Thus individuals find that they are able to deal with day-to-day adversities more effectively. Re-socialisation enables individuals to accept and take on new roles and responsibilities in their lives, such as re-establishing their family ties.

CHAPTER SIX - DISCUSSION

6.1 Introduction

This chapter provides a discussion of the findings of the study in relation to current literature. The literature review presented in Part I of the thesis offers a general overview of the issues of homelessness and TB. However, this review was developed prior to Grounded Theory data collection and analysis. As recommended by Glaser, and explained in Section 4.6, it was important that the researcher avoid bias through a literature review prior to generating Grounded Theory. As cautioned by Glaser (1998), the researcher made a conscious effort to place the literature review in the background and to allow the Grounded Theory to emerge. The time lapse of more than a year between the initial literature review and data gathering aided this process.

When interviewing began, the researcher asked participants to openly describe their day, and what was happening in their lives. It soon became evident that there was a considerable amount of turmoil and change in there lives, extending well beyond the issue of having TB. The participant's description of their lives, and the struggle they faced, developed and formed the process of Survivalising. As data analysis progressed, Survivalising emerged as the Grounded Theory explaining the homelessness/TB experience.

The researcher reviewed relevant literature during the sorting and writing-up stage of Grounded Theory, as the theory of Survivalising was almost complete and had reached saturation. Thus, she was later able to interweave the literature as a source of additional data for constant comparison. This process enabled the researcher to be open to emerging concepts, rather than preconceived ideologies, and thereby understand what was truly taking place in the data (Glaser 1998).

6.2 Current Literature & Theories

Although some studies within the initial review supported a particular property or part of a category of Survivalising, no comparable theories or studies to Survivalising

were found. Thus, the initial literature review failed to systematically reveal the connections of the basic social process of Survivalising that had emerged from the current study. Within this context, it is argued that the theory of Survivalising adds to the body of knowledge. A further strength, and contribution to the literature, is that the present study elicited data directly from those experiencing homelessness and TB. As a result, it provides a relevant theory that is both meaningful to those experiencing the homeless/TB phenomenon and to professionals caring for them. Furthermore, the theory of Survivalising challenges certain preconceived assumptions evidenced in previous studies that contain value-laden conceptualisations of deviant behaviour among the homeless.

In summation, current literature contributes insufficiently to our conceptualisation and understanding of the homeless TB phenomenon, as the majority of literature focuses on the medical and quantifiable aspects of TB, or on issues related to homelessness other than TB. When addressing the unique nature of homeless individuals with TB, prior theories and studies are piecemeal, fragmented and not located within a broader theoretical framework. The current study delves further and deeper into the homeless/TB phenomenon and the results build on and expand what was already known. The current body of literature does provide support and corroboration to the findings of the current study and adds breadth and depth to the theory of Survivalising.

6.3 Survivalising

6.3.1 Zoning-out

Zoning-out is a powerful concept that describes the participants at a stage in their lives when they are merely drifting and describes their daily quest to survive. Zoning-out was especially prominent in the current study, as it was the phase in which most of the study participants had spent the majority of their time while homeless.

A literature search of the concept of zoning-out and similar concepts did not produce results. The only reference to 'zoning-out' is in the discipline of clinical psychology, describing it in terms of daydreaming, for instance among children linked to behavioural problems and autism (Mind Works 2007).

Intense reading in other substantive areas, and attending a number of Grounded Theory workshops, increased the theoretical sensitivity[19] of the researcher. This process of enhancing sensitivity to the data enabled the researcher to be receptive to abstract concepts and conceptualisation of the theory of Survivalising. The experience allowed the researcher to not only discover zoning-out as a category and stage of Survivalising, but provided increased sensitivity, which assisted in relating theoretical terminology to the emerging theory. The term zoning-out encapsulates the three properties of cycling, strategy and divergency and substantiates it as a new concept.

The term cycling is adapted from Glaser's Theoretical Coding Family[20] (Glaser 1978). In the context of this study, it relates to a complex process describing the individual moving from place to place - or from 'sofa to sofa'. It is paradoxical that it is a phenomenon of motion, but at the same time individuals remain in a stagnant state. Cycling describes a vicious circle, in which the individual takes whatever life throws at them. The intense motion of cycling makes rational thinking problematic, as plans for the future become abstracted by day-to-day exertions.

Within the current literature, there are few theories directly comparable to the notion of cycling. However, Bottomley's (2001) study, presented in the literature review (Chapter Two), describes the constant movement of homeless people and portrays them as mobile individuals that often walk for miles each day and are relentlessly told to move away from shops, restaurant doorways, park benches and public places. Although Bottomley's (2001) study supports the present findings, it only considers

[19] See Chapter Four for more on theoretical sensitivity.
[20] Theoretical Coding Family is described in Section 4.5.7.

the physical impact of constant moving (for instance oedema and foot deformities), neglecting the psychosocial effect and missing the theoretical element, or notion, of cycling as an outcome of such movement. Bottomley's (2001) study is argued to be descriptive in its nature and therefore does not provide any theoretical underpinning.

Coping with violence is part of the cycling condition, and the problem of violence imposed upon the participants was particularly common among those who are zoning-out. The fear of violence was a constant experience and intense danger was felt on a daily basis.

Grenier's (1996) findings, also reported in Chapter Two, provide insight into the experience of violence and support the results of the present study, i.e., that the phenomenon of homelessness is unpredictable due to constant struggle and violence. Although Grenier's (1996) study limited its population sample to elderly homeless people, it is valuable in highlighting the present findings that dealing with violence is part of the homeless experience and is a component of the cycling condition. The result of the violence for the individual is insecurity and stress.

The current study found that the cycle of fear also led to sleep deprivation. Other studies present similar results, finding that sleep deprivation was common among the homeless, due to the stress from fear of violence and crime (Davis & Shuler 2000, Gardiner & Cairns 2004, Bottomley 2001). This sleep deprivation has commonly been described in terms of a bio-behavioural framework. To illustrate this, a study by Davis & Shuler (2000) looked at the interactions among psychosocial and environmental stressors and the hypothalamus-pituitary-adrenal-ovarianimmune axes to explain altered sleep-wake patterns in homeless women. Their U.S. based study investigated the self-reported sleep patterns and lifestyle factors associated with the sleep of 50 homeless women, between 18 and 44 years of age. The results from their study revealed that the majority of the women reported sleep deprivation and almost half of the women slept six or less hours a day. In support of the current study findings related to the affect of strategy in substance use, Davis & Shuler (2000)

found that alcohol use, cocaine, anxiety, depression, loneliness, and concerns about safety and money were factors significantly related to altered sleep patterns. As with other studies, Davis & Shuler's (2000) work lacks a conceptualisation of the problem, and is limited to descriptive linkages to the physical effects of lack of sleep. However, their study does highlight the problem of depression and loneliness among the homeless population, which was also found within the concept of cycling in the current study. These findings are also corroborated by Pleace *et al's* (1999:30) study that found that people sleeping rough frequently reported feelings of isolation and stress.

To cope with the cycling experience, homeless people employ strategy. The majority of participants in the current study were using substances as their strategic coping mechanism for dealing with their turbulent social world. Participants found comfort in the chemicals they took. Substance use enabled them to cope by forgetting or numbing themselves against their physical and psychological environment, forming a state of escape.

There are a number of studies that support this finding and report the serious problem of substance use among homeless people (Griffiths 2002, Pleace *et al* 1999, Pleace 1998, North *et al* 1996, Gill *et al* 1996, Anderson *et al* 1993), some of which were discussed in Chapter Two of the literature review. Pleace *et al* 1999, for instance, found that rough sleepers were more likely than the general population to have an alcohol or drug dependency problem. Griffiths' (2002) study found that 70 percent of homeless people misuse drugs and half were dependent on alcohol. A national study on homelessness by Anderson *et al* (1993) also reported similar findings on substance use among homeless people, stating evidence of heavy drinking or alcohol-related health problems, particularly in those sleeping rough. The use of heroin and other opiate-based drugs are also known to be frequently used by homeless people (Gill *et al* 1996).

Although many studies report the problem of substance use, few have linked it as a coping method. However, the Bines (1994) study does make this link, and reports

that alcohol use was found to be a coping mechanism to deal with difficulties homeless people faced in their lives. While various studies have reported the high level of substance use among homeless people, the majority of these studies have ignored the underlying reasons that lead so many homeless people to engage in such activities. The current study adds to the body of knowledge, and provides valuable insight into substance use as a strategy.

In addition to alcohol, drug use is commonly tied to homelessness. A relevant and theoretically based study by Kearney *et al* (1995) about 'mothering on crack cocaine' discovered that when children were forcibly removed from their mothers, mothers often increased their crack cocaine use to cope with the loss. Kearney *et al's* (1995) study found smoking crack was a social activity that provided short-term relief from the constant worry about their children. Although Kearney *et al's* (1995) Grounded Theory does not encapsulate the entire theory of Survivalising, the findings confirm the notion of substance use as a strategy for coping and are consistent with the current concept of zoning-out.

The findings from the current study also suggest a relation between substance use and crime. Participants were likely to both engage in substance abuse and have repeated contact with the criminal justice system. This led to increased stress for the individual, and participants described the issue of crime and the drug scene as a dangerous underworld. Likewise, a study by Randall & Brown (1999), involving interviews with 120 homeless people and staff from 19 different homeless projects in London, found that around half of the people sleeping rough had been in prison and many had frequent contact with the criminal justice system.

Although the finding of Survivalising points towards individuals being extremely 'busy' with maintaining their zoning-out state through substance use, there are no available studies with which to compare this result. The new finding is important as it indicates that those zoning-out are in a constant state of being busy, whether this is in the form of taking substances, or finding money to pay for their addiction. Sustaining the strategy for zoning-out is physically and emotionally challenging. The

results also suggest that individuals often had to do things they did not want to do, such as commercial sex work, begging, or theft. These activities become methods for financing substance use and are clearly elements of zoning-out. Drake *et al's* (2005) research report corroborates the findings of the current study, demonstrating that because of poverty, some women (and men) may sell sex for money to pay for their drug addiction.

The current study takes exception to the generalisation that homeless people are deviant (NFA 1974 cited by Fisher & Collins 1994), as its findings suggest that begging, commercial sex work or theft are not simply activities done by 'bad' people. Rather, these activities (or behaviours) are part of Survivalising, and are recognised to involve considerable risk. In other words, these behaviours are not simple moral choices or acts of deviance, but demonstrate a complex, but practical survival strategy.

While the above demonstrates some of the special concerns and needs of the homeless, individuals in the current study had serious problems in simply obtaining basic needs such as food and shelter. While they understood the significance of not eating, the recurring compulsion to take part in harmful substance use outweighed the desire to look for food. Conversely, individuals' daily activities revolved around substance use. Thus, their basic needs were controlled by the property of strategy within zoning-out.

Maslow's (1954) hierarchy of needs provides an important theory on needs and motivation. The model is depicted as a pyramid, with the most basic needs illustrated at the base. These include physical requirements of air, water, food, sex. At the next level are safety needs of security and stability, followed by psychological or social needs of belonging, love and acceptance. At the top of the needs pyramid is self-actualizing needs, which is the need to fulfil oneself. The peak experiences of self-actualization are described as intense feelings of love, understanding and happiness, when the individual feels 'whole'. The theory suggests that unfulfilled needs lower on the hierarchy inhibit an individual from moving to the next level. In relation to the

current study, a limitation of Maslow's (1954) theory is that it does not explain how homeless individuals often neglect their basic needs in pursuit of higher ones. For instance, participants in the study often would neglect basic needs such as food and shelter and instead would take part in substance use to attend their emotional needs. Maslow's (1954) theory does not explain this conflict of needs. However, the concept of strategising in zoning-out does appear to explain this event.

A study by Barnhoon & Adriaanse (1992) finds that lower income classes have survival needs that actually compete with one another, a finding that also emerged from the current study. Barnhoon & Adriaanse (1992) discovered that health care and treatment needs compete with more pressing needs, such as finding shelter. This has clear linkages to the problems homeless individuals have with drug adherence. If basic needs are un-fulfilled, taking TB medication may be a lower priority (Barnhoon & Adriaanse1992, Kushel *et al*, 2001).

Within the current study, the concept of strategy (zoning-out) resulted in personal health often considered a low priority by the homeless. This reflects the complex condition of homelessness and explains why personal health is often neglected. A similar finding can be found in Power & Hunter's (2001) results which discovered that more than half of their sample worried about financial issues (53 percent) compared to only 30 percent who often worried about their health (Power & Hunter 2001:595).

A more detailed analysis of the complex issue of homelessness and its impact on access to health care has been reported in the literature review presented in Chapter Two (see Section 2.15). A great deal of literature, and numerous studies, describe and detail the problems that homeless people face in accessing health care (Story *et al* 2007, Story *et al* 2004, Rayner 2000, Grange & Zumla 1999, McMurray-Avila *et al* 1998, Robertson & Cousineau 1986, Grenier 1996, Shiner 1995, Pleace *et al* 1999 Townsend *et al* 1992, Jackson 1996). However, this body of evidence only acknowledges that access to health care is a problem, and that keeping follow-up appointments for continuous and comprehensive care is difficult due to conflicting

needs and priorities. The findings of the current study, particularly the concept of zoning-out, provide a conceptual explanation for the problems of poor access to health care. The theory of Survivalising provides a holistic theoretical framework for understanding the problem and increases our knowledge from the viewpoint of those experiencing it.

Another property of zoning-out found in the current study, divergency, involves the individual separating themselves from others by their divergent sense of self. The concept concerns the individual digressing from prescribed social norms and identities, brought about by the conditions of cycling and strategising, and leads to stigmatisation.

In searching for theories of stigma, the most prominent, influential and applicable to the findings of the study was that of Erving Goffman. His famous work on stigma is published in the book titled *Stigma: Notes on the Management of Spoiled Identity* (Goffman 1963). Goffman (1963:3) defines stigma as ‘‘an attribute that is deeply discrediting’’ and points out that the stigmatised person is reduced ‘‘from a whole and usual person to a tainted, discounted one’’. Goffman’s (1963) position is that the processes of social construction are key and explains stigma as ‘‘a special kind of relationship between an attribute and a stereotype’’ (Goffman 1963:4) and maintains that stigma is embedded in a ‘‘language of relationships’’ (Goffman 1963:3). Goffman’s theory suggests that stigma occurs as a discrepancy between ‘‘virtual social identity’’ (how a person is characterised by society) and ‘‘actual social identity’’ (the actual attributes of a person) (Goffman 1963:2). ‘Perceived stigma’ transmits into a person communicating their own experience of being stigmatised, and reflects the amount and type of stigmatisation experienced.

The results of the current study, found participants were indeed stereotyped by non-homeless individuals. This was related to their homeless status, for instance in the assumption that the homeless individual would steal from them. The self-perceived stigma communicated by individuals in the study was one that, as a result of their

marginalisation, would portray themselves in a poor light, highlighting their extremely low self-esteem.

Goffman (1963:3) categorised stigmas by their features and describes them in three ways: as 'abominations of the body' or uninherited physical characteristics; 'blemishes of individual character' connected to personality or behaviour; and 'tribal stigma' (devalued groups). The subjective experience of stigma, varied depending on the type of condition the individual faced. In essence, all three of the above categories related to the experiences of the participants in the current study. This is highlighted in several ways. The first relates to the notion of 'abominations of the body' and can be paired with the stigmatising elements of the disease of TB. Being diagnosed with TB was found to be a major stigmatising factor. The second feature regarding 'blemishes of individual character' links-up with views of homeless people's personality and behaviour. For example, individuals in the study who engaged in substance use felt stigmatised due to their behaviour. The third concerning Goffman's notion of 'tribal stigma' relates directly with the idea that the homeless are devalued and viewed as a problematic group of individuals. Goffman's theory is important in its support of many of the findings from the current study that established stigmatising issues as one of the key areas of concern among participants.

As highlighted in Chapter Five, the subjective experience of stigma among the participants in the study varied and was dependent on the individual's situation. For instance, those who were homeless and had TB felt stigma from both factors: the social issue of homelessness and the disease (TB). The degree of an individual's homeless situation was also an important factor, for instance, if they were a rough sleeper their visual appearance to the public increased their degree of stigma. Those who were also engaged in substance use had the added stigma of being a 'drug addict'. This additional stigma caused further marginalisation.

The view of the 'contagious' nature of TB creates stigma, as it is conceived to pose a serious risk to health and thus a perceived treat to others. Furthermore, participants who had the added diagnosis of HIV suffered an even more compounded stigma due

to the fear of others discovering their condition. With many communicable diseases, there is a perception that the individual shoulders some level of the blame for acquiring the illness (Breitkopf 2004), and the sense of stigma is deepened when the illness was thought to be the fault of the individual.

Goffman (1963) described stigmatised individuals as 'reduced in our minds from a whole and usual person to a tainted, discounted one' (Goffman 1963:3), and 'not quite human' (Goffman 1963:5). The explanation of those stigmatised essentially divides society into 'normals' and those having a damaging attribute (a stigma). Although Goffman's (1963) representation of those that are 'normal' and those that are not, are rather dramatic and an extreme construct, the study found this to be the experience and perception of many of the participants who narrated their perceptions of not feeling 'normal'.

Goffman's (1963) concept of the gulf between those who are 'normal' and those that have a stigma, links with the findings of the current study, in which participants described their sense of social divide between themselves and non-homeless people. This feeling of separation from 'normal' society often left the individual feeling detached from 'normal life'. Although individuals in the current study were found to be de-sensitised and accustomed to their difficult existence, they still experienced stress from feeling 'left out' and marginalised. Participants often described how embarrassed they felt due to the reaction of others, for instance their general appearance as a homeless person or when others discovered they had TB. Essentially, they were left feeling isolated and alone.

Regardless of their divergency, individuals still desired normality. Nonetheless, within the conceptual ordering of zoning, there was a clear contradiction with their vision of normality and their actions. Most individuals did not want to leave their world of zoning. Therefore, the desire for normality merely becomes a passing consideration, but not a reality. Prochaska & Diclemente (1982) developed the cycle of change model, which conceptualises change as a cycle. The model includes the notion that relapse is part of the cycle of change and a normal process. While the

model does not explain the state of zoning-out, it does compliment the concept of divergency, and supports the finding that it is difficult to move away from zoning-out. While individuals may regularly contemplate change, they do not put forward a concerted effort to realise the change due to difficulties highlighted in the issues of cycling and strategising (see Chapter Five).

Although at a conceptual level, there were no comprehensive theories on the notion of divergency found in the literature, some studies have indicated that homelessness leads to intense alienation and the loss of essential social skills (Pleace *et al* 1999, Fisher & Collins 1993). This finding is important in supporting the results of the study, which suggest individuals were marginalised and often could not engage with non-homeless people due to divergency and this influenced their social skills.

Embedded in the homeless situation was discrimination (closely tied to stigma) from various sources, including professionals (access to care), the public and even other homeless people. According to Breitkopf (2004:4) "stigma is an interactional process, defined within societies, in which particular social identities are collectively devalued". This construct of stigma was found to be what many of the participants in the study experienced. The impact of stigmatisation and discrimination commonly influenced the individual's self-esteem, making them feel emotionally low and of little value to society as a whole.

Masson & Lester's (2003) study found that the stigmatising attitudes of doctors created significant barriers to health care for homeless people. Using a mixed methods design, they applied a structured questionnaire to 211 medical students two weeks before they commenced medical training and followed up during their final clinical placement five years later. The semi-structured interviews were used to examine in depth 12 students that displayed the greatest degree of attitude change. Interestingly, the results of their study indicate that medical students' negative attitudes regarding homeless people increased toward the end of their medical training. Masson & Lester's (2003) research corroborates the findings of the current study and highlights the problem of access to health care due to stigma from

professionals. Participants from the current study felt that stereotyping from professionals affected access to essential services.

Specifically related to TB, a number of studies have examined the issue of poor adherence to treatment among homeless people (Tedeschi 1997, Barnhoon & Adriaanse 1992, Pablos-Mendez *et al* 1997). The majority of participants from the present study found that the experience of zoning-out impeded their ability to attend clinic for TB treatment. The study discovered that the main concerns for individuals not taking their TB medication was dealing with the immediate needs within zoning-out. The majority of the individuals who were zoning had at least one form of substance addiction, which ultimately influenced their adherence to TB treatment.

Power & Hunter's (2001) London based study, which conducted interviews with both homeless people and professionals working with them, found that TB was a health concern among homeless people. This finding, however, contradicts that of the current study, as the majority of the individuals did not realise that they had TB. They initially thought that their symptoms were due to their zoning life style and did not consider TB as a concern. When it was diagnosed, it came as a great shock.

Studies have found that being homeless was significantly linked with poor adherence (Rayner 2000, McMurray-Avila *et al* 1998, Jackson 1996). Unfortunately, these studies often hold homeless people solely responsible for poor adherence, rather then focus on the issues of stigma and discrimination that impact health seeking behaviours, access to services and the quality and appropriateness of the care provided. This study result is supported by Martin *et al* (1992), Connelly & Crown (1994) and Pleace & Quilgars (1996), which found that health professionals often held negative views of the homeless.

According to Pleace *et al's* (1999) research, homelessness was found to be associated with 'deviant' or challenging behaviour. Similarly, a study by Martin *et al* (1992) reported that health professionals often held views that homeless people were in part

to blame for their medical condition, for instance because of substance use. However, Grange & Zumla (1999) disagree with this ideology of deviance and blame, and support the current findings, suggesting that while those with adherence problems are often held accountable, responsibility should be placed upon health professionals.

6.3.2 Bottoming-out

Bottoming-out was found to be a personal crisis point experienced by a number of participants in the present study. The crisis point moves the individual to a new state, resulting in them bottoming-out. Individuals were found to experience acute vulnerability and intense fear in this phase of Survivalising. Bottoming-out often occurred due to hospitalisation or the diagnosis of TB resulting in individuals hitting an all time low. The experience meant that individuals were unable to view themselves, or their world, in the same light. This event formed a critical juncture for the individual and was a potential catalyst for change. Although the discovery of bottoming-out was fundamental to the process of Survivalising, there are no comparable studies or current theories with which to compare. However, there are peripheral studies that relate to elements of the theory, but do not encapsulate it in full. For instance, the Bines (1994) study, reported in the literature review (Chapter Two), found that many homeless people suffered depression.

6.3.3 Self-realisation

The term self-realisation is adapted from Glaser's Theoretical Coding Family[21] (Glaser 1978). In the context of this study, it relates to an important turning point in which individuals assess themselves and their lives. Individuals who were undergoing self-realisation found an increased clarity of personal needs and interest in health and social services, thus adherence to TB treatment improved.

Individuals who were self-realising accepted that they are on a new and important path towards healing, and is a condition that is personally experienced and thus can neither be taught nor imposed.

[21] Theoretical Coding Family described in Chapter Four.

The current study found that if individuals were stigmatised, and did not receive appropriate treatment by health professionals, they were at risk of going back to zoning-out - rather then continuing in the process of Survivalising towards healing. However, when health professionals interacted effectively with the participants and showed them respect, they were able to cultivate positive relationships, which inevitably promoted the individuals towards healing.

The researcher faced difficulties in finding comparable studies or relevant theories on the concept of self-realisation. Much of the available information focused on self-realisation as a religious experience. However, the notion of 'cultivating' positive relationships has been studied by Simmons (1993). Simmons' (1993) Grounded Theory study of milkmen in the US on 'cultivating relationships' with customers explains how shifting social structures and economic factors transformed the milk industry from one involving straight forward milk delivery to one focused on the need to 'cultivate' relationships. With improved relationships came increased profit.

The theory of cultivating relationships provides support for the important role health professionals have in cultivating positive relationships with homeless people. The importance of showing homeless individuals respect has been shown to impact treatment adherence and follow-up care. In agreement with this idea, are the findings of a study that reveals that satisfaction with health professionals contributed significantly to the continuation of TB treatment (Barnhoon & Adriaanse 1992).

As discussed in Chapter Two, homeless people may refuse treatment for a variety of reasons. It is evident from the current study that zoning-out influences service access and treatment. The use of outreach teams (see Chapter Two), which emphasise relationship building between health service and the homeless, may be of significant value as a method of persuading individuals to accept help. The benefits of establishing respect, rapport and trust were all found in the current study to be significant factors for individuals to move through the process of Survivalising. Outreach, as described by McMurray-Avila *et al* (1998) could be a valuable means for breaking down barriers to effective TB treatment highlighted in the current study.

6.3.4 Healing

Healing is a substantive term discovered in the data describing individual concerns for *normalising* - influenced by re-socialisation and changes in psychological constructs. This process forms a new personal direction that sees the individual 'fixing' their life through restoring their health and addressing other personal issues. The key to healing is that the individual makes a concerted effort to engage with service providers and rekindle family and social relationships. During the process of healing, adherence to TB treatment becomes a priority, as do other health issues.

The concept of fixing is about the individual mending areas of their life that were previously neglected. Individuals become active participants in healing, whether it is in the area of housing, health, employment or family relationships. Furthermore, individuals find the value of other healing activities such as in drug rehabilitation.

With an increase in fixing activities, the individual enters a new world of social interaction where they form social support networks. The networks are linked to their healing agenda such as TB care, drug dependency units (DDU) and housing services. By maintaining close links to these networks, re-socialisation and further normalisation is developed. Social interaction also increases feelings of well-being and self-esteem. Participants recognised that the degree of adversity was considerably reduced once they reached this phase of Survivalising, particularly as they found their basic standard of living improved as a result to their efforts of addressing issues such as housing.

On the concept of fixing, Tosi's (2005) Italian-based study supports the finding of the current study, as it measured marked improvements in the quality of life of homeless people who were re-housed in 'normal' accommodation. Tosi's (2005) study found that the social reintegration process of housing was powerful in forming a sense of normality among homeless people. The study reflects the concept of normalising, which was a significant factor in the theory of healing. Within healing, the desire for normalising is strong and individuals were found to immerse themselves in the process of re-socialisation. Re-socialisation provided the individual

a way to communicate their needs by engaging with service providers, which in turn increased re-socialisation through interaction from professionals.

The current study found that 'normalising' increases an individual's sense of hope for a more 'normal' existence. Partis's (2003) phenomenological study revealed the meaning of hope as it occurred in the lived experience of seven homeless people. The study identified strategies that were used to maintain hope and provides a theory comprised of a number of important themes:

- *expectancy* with hope experienced as future imagined reality;
- *connectedness* perceived as a meaningful relationship between self and others which sustained hope;
- *view from the street* experienced relating to hope and hopelessness;
- *emotionalism* expressed as contradicting emotional conditions which either reinforced or dwindled their sense of hope; and
- *brokenness* that expresses feelings of depression due to the harsh conditions of homelessness - reducing their feelings of hope.

Partis's (2003) study provides a clear understanding of the meaning of hope, from a homeless person's point of view, that the current study only superficially addresses. Thus, Partis (2003) goes further then the current study in this area and provides important insight into the meaning of hope within the context of homelessness.

As participants advanced though the healing phase, they were found to be better able to cope and were more successful in dealing with difficult issues in their lives, thus facilitating their process of healing. Perrott *et al* (1998) undertook a qualitative study of coping strategies used by 40 women who reported sexual abuse in a postal questionnaire and found that 'seeking social support was associated with more adaptive outcomes' (Perrott *et al*, 1998:1137). The Perrott *et al* (1998) study concurs with the findings of the current study and suggests that social support promotes resilience. Although the Perrott *et al* (1998) study was not based on a homeless

population, it illustrates the importance of social support as a means for re-socialisation and increased capacity for coping.

6.4 Limitations

Methodologically, this study stayed as close as possible to the classic Grounded Theory approach of Glaser & Strauss (1967) and Glaser (1978, 1996, 1999, 2001, 2002). Therefore, it is argued that at a methodological level there are few limitations.

Earlier in this thesis, Survivalising was described as a basic social process, which may occur in various contexts and substantive areas. Because it is a newly discovered basic social process, more studies need to be conducted to develop the current theory of Survivalising from a substantive theory to that of a formal theory. Consequently, the theory of Survivalising is limited in its disposition to our understanding of a process in which homeless people with TB engage.

A number of other limitations are listed below:

- The sample population consisted of sixteen participants based in London and therefore generalisations cannot be made due to the small sample size and limited locality.
- The sample was comprised of participants who volunteered to take part in the study and were willing to discuss their experiences. Consequently, other homeless people, possibly those most vulnerable and unwilling (or unable) to talk, could not be represented in the theory.
- Participants were recruited from TB clinics where they had some form of support from staff, thus adding bias to the sample population.
- The Grounded Theory of Survivalising is the first of its kind, so there are no direct comparative theories with which to evaluate it.
- The theory is limited to the experiences of homeless people with TB in London, and does not incorporate the experiences of health professionals. This limits its scope to that of service users rather then practitioners.

6.5 Conclusion

As discussed in the earlier literature review chapter (Chapter Two), the majority of research on TB has been conducted through a quantitative lens. Little was previously known about the meaning of TB to homeless people, and how they cope with it their lives. Even though studies have found a strong relationship between homelessness, TB and poor adherence (Story *et al* 2007, Pablos-Mendez *et al's* 1997, Evans 1995, Sumartojo 1993, Weise *et al* 1994), there was a fundamental gap in our knowledge for treating and caring for homeless people with the disease.

At a conceptual level, the homeless-TB experience, and its meaning to homeless people, was scarcely researched. The problem in much of the literature to date is that the majority of studies focused on treatment interventions and did not incorporate homeless people within their samples. Consequently, the body of knowledge offered only a peripheral view of the problem, with no in-depth understanding of the homeless-TB experience. As the current study focused on the perspectives of homeless people, it was able to provide a unique insight into their world.

The current study addresses a gap in literature through the discovery of the Grounded Theory of Survivalising. As outlined in this chapter, many parts of the theory are supported by research and found evident within the body of literature. Survivalising is a newly discovered basic social process, which goes further than other descriptive studies by clearly explaining the process in which homeless people with TB engage. The theory builds on the literature to date and extends understanding of the meaning of TB among homeless people. It also provides a theoretical framework that health professionals can apply to increase their understanding of homelessness and TB and improve the appropriateness, comprehensiveness and quality of care of this vulnerable group.

CHAPTER SEVEN – IMPLICATIONS & RECOMMENDATIONS

7.1 Introduction

This chapter describes the implications and recommendations resulting from the research findings. It begins with a general discussion and subsequently explores the possible impact of the theory for health professionals. Table 5 in this chapter, sets out a tool developed from the findings of the study and could contribute to understanding and improving the care of homeless individuals with TB. Finally, the potential implications and recommendations for policy are presented.

7.2 General Implications

To improve the care of homeless people diagnosed with TB, it is important to build upon the current body of knowledge. Theories form a significant role in this process by making the link between knowledge and practice (Parahoo 1997). It is therefore vital to explore the potential implications of the theory of Survivalising on health care practice and policy.

The theory of Survivalising was discovered by the researcher using a methodical and systematic process using the Grounded Theory method. Survivalising is purely an interpretation of the phenomenon of TB among the homelessness. Like all theories, Survivalising is not a definitive explanation of the phenomenon, as it can be modified over time. It does however provide a theory encompassing a set of interrelated concepts that present a systematic view of TB and homelessness. Although Survivalising is theoretical and abstract in nature, it is grounded in research data and provides a number of concepts, which form propositions and clear and practical implications (see Chapter Five).

By using the Grounded Theory method, the researcher was able to understand the substantive problem of homelessness and TB, from the point of view of the homeless themselves. The theory was discovered by investigating the individual's main concern, and the actions and behaviours that constantly revolved around their

attempts to address this concern (Glaser 1998). This re-emerging main concern was found to be Survivalising and thus the basic social process. Survivalising was the dominant pattern that emerged from the data, and enables us to understand the social process in which homeless people with TB engage in.

There are three important implications that have come from the study. The first is that the findings address gaps in knowledge through the investigation into the homeless TB experience, adding new insight to the existing body of literature. The second implication is that the theory of Survivalising expands our knowledge, understanding and conceptualisation of the homeless problem. Third, but most important, it adds the voice of homeless Londoners diagnosed with TB to the evidence base, with perspectives that have been absent from other studies.

7.2.1 Implications & Recommendations for Health Care Practice

As explained in Chapter Five, Survivalising presents a theory that explains the experiences of homeless individuals with TB. The theoretical model of Survivalising provides a means for practitioners to analyse and tackle the growing problem of TB in marginalised populations. Survivalising is a theory, but one with clear implications to practice. Although TB was not found to be a main concern of participants, it was a significant concern, and one that presented an entry point to improving these individuals' lives.

Additionally, the findings indicate that health professionals have a fundamental impact upon the process of Survivalising. Their role became clear, principally when participants had bottomed-out (and in self-realising) and they experienced stigmatisation due to the behaviour of some health professionals. This potentially increased the risk of the individual being lost to treatment follow-up and returning to zoning activities - as opposed to moving toward self-realisation. The evidence also points to some participants moving directly from zoning-out to self-realisation. As described in Chapter Six, this was often due to positive relationships with health professionals, which increased the individual's self-worth and became an important factor in their adherence to TB treatment. This was credited to support from health

professionals in providing the appropriate care for their illness. Equally important, was the appropriate treatment of the individual, and the respect and rapport between homeless individuals and health professionals.

Stigmatisation of the homeless is an important issue and can deter people from seeking help. Addressing the stereotypes that affect homeless people is therefore a key challenge in improving the services available to them**.** It is recommended that health professionals work more effectively and closely with this vulnerable group. It is clear that effective face-to-face interaction with health professionals, and a positive hospital experience, enabled participants to increase their understanding of TB. With the increase in health education and their own knowledge and understanding of TB and its consequences, individuals felt empowered and able to move towards healing.

Understanding the process of Survivalising could enable health professionals to assist homeless individuals throughout the process, from zoning-out to healing. The theory provides a tool to guide services and the homeless individual through their care. Because the model is grounded in real life experiences, it is a practical tool for recognising the stage homeless individuals are in within the Survivalising process. The tool can also provide justification for individuals receiving certain services.

Survivalising enables the health professional to assess where the individual is, to analyse where they are moving toward and to establish an action plan of how to address their TB/homeless problem. As a result, the individual is provided with appropriate treatment for TB and appropriate treatment for them as an individual.

Zoning-out is the most difficult phase due to the chaotic day-to-day cycling events, strategising and diverging elements. The self-survival element of cycling means that individuals have a lack of social support and are constantly adrift. The insecurity from cycling needs to be addressed by attending to issues such as housing, which would remove some of the fear associated with violence and theft and lessen the harsh conditions faced on a daily basis. For health professionals, it is important to

recognise issues from the point of view of the individual experiencing them, and be able to assess to what degree they are zoning.

Strategy (see Section 5.3.2) provides the individual with a way of managing their social world, often leading individuals to engage in substance use. Practical interventions such as referral to DDUs could provide individuals with an opportunity to remain 'busy' in rehabilitation as a strategy rather than engaging in substance use, and health professionals should consider this as a critical care option for those in need. Health professionals also can play an important role in educating other professionals about their role in social stigma and how they can prevent individuals from becoming further marginalised and socially excluded. Reconceptualising the 'deviant' nature of such behaviour is fundamental if health professionals are to de-stigmatise and deal with the issues of social exclusion.

The findings from this study clearly point to the individual's desire to end substance use, but cycling and the fear of substance withdrawal leave individuals with little control over their actions. Consequently, new choices need to be offered regarding service support.

Removing the problematic nature of diverging is difficult, since it is partly due to the individual's sense of himself or herself. The results of this study highlight that individuals craved a social unit and that this could be provided by social support networks. Health professionals could both assist with and provide these networks.

Evidence from this study shows that the TB diagnosis (or hospitalisation) can cause a crisis point, which can 'shock' the individual out of zoning-out. It is during the state of bottoming-out that health professionals have a powerful influence on the progression of individuals through the process of Survivalising. Knowing what to observe, such as a state of intense fear, hopelessness or depression is vital. However, dealing with the stigma is again paramount if individuals are to move forward and not regress to zoning-out. The findings from the study recommend that developing

trusting relationships and showing respect towards the individual are important factors to move out of the bottoming-out stage of Survivalising.

Although the state of self-realisation comes from the individual, health professionals are again encouraged to provide services according to the needs of individuals. When individuals examine new meaning for their lives, a range of services need to be offered. Individuals can take up new opportunities, such as in ceasing or reducing substance use – with appropriate care. While especially pertinent at this stage, health education is imperative at all stages of Survivalising. This is demonstrated by the observation that most individuals in this study did not realise that they were ill due to TB, but attributed it to their lifestyles. Health education can both improve health behaviour and encourage individuals to seek and accept professional help.

During the phase of healing, individuals are more open to proposals of help from service providers. With their new agenda for change, the concerted efforts of the individual enable them to fix their lives. In healing, normalisation is a process of accepting the need for a 'normal' life. Re-socialisation helps them to achieve this, and contributes to improved adherence to TB and substance use treatments. It also provides individuals with a new outlet for coping in their lives. The overall result of healing is that the individual copes more effectively and develops new priorities -and thus a new social world.

7.2.2 Implications & Recommendations for Application of Findings

In March 2007, the researcher presented the study findings to over fifty TB nurse specialists from thirty-three TB clinics in London at the Health Protection Agency[22]. The presentation was entitled *TB and Homeless People - Experience in London* and focused on disseminating the results from the study. The emphasis was on circulating the theory of Survivalising as a practical tool for the front line Lead TB nurses. The implications and recommendations covered earlier in this chapter were outlined and the Survivalising - Themes, Context, Practice and Care tool (see Table 5), developed

[22] Health Protection Agency. The London TB Nurses Network Development Session – 03/04/2006

in consultation with the Health Protection Agency, was disseminated. TB nurses had the opportunity to ask questions and offer feedback. It is important to note that although the tool is grounded in its theoretical form and was developed from the findings of the study[23], aspects relating to practice need to be further evaluated and validated. Therefore, further studies are required to verify its effectiveness as a tool for health professionals. Nonetheless, early feedback from TB nurses, and discussions with homeless participants (see Section 4.7), confirm its potential benefits to practice.

The Survivalising - Themes, Context, Practice and Care tool presents health professionals with a tool, which lays out the implications of the theory and its theoretical application for health professionals. The diagrammatic structure, in the form of a conceptual framework, illustrates how the theory, concepts, practice and policy are related in the application of the theory. Its aim is to facilitate a broader understanding of Survivalising among health professionals, with the desire that they will also use it to inform other colleagues.

The first section of the tool, titled Narrative themes, displays examples of quotes to demonstrate the groundedness of the data and features the four phases of Survivalising. The quotes are presented to show the meaning of the phenomena of homelessness/TB from the perspectives of those experiencing it. This is central to the conceptual framework and to facilitate understanding of the theory. With this tool, the abstract nature of Survivalising translates to a more practical level.

The second section of the tool outlines the TB context and its relation to the four phases of Survivalising. This provides structure on the situational issues related to TB under each phase of Survivalising.

[23] With consultation from the Health Protection Agency.

The third section, titled Practice and Care, displays the practical implications of the TB context and suggests appropriate care that could be implemented[24]. This section is important because it provides the basis for thinking about what health professionals can do by connecting health care services and their actions to the views and experiences of homeless individuals with TB – all grounded in concepts that emerged from the research.

The tool can help health professionals to determine, rationalise and justify the best way to care for homeless individuals diagnosed with TB. It can explain why certain actions are taken, and not others, at different points in their care. For instance, by establishing the stage at which individuals are at in their Survivalising process, health professionals can better assess an individuals needs, determine and form individual care packages and implement appropriate care.

Homeless individuals with TB could personally benefit from understanding the process of Survivalising. Health professionals can convey this information to empower individuals with the knowledge that they are able to reach the phase of healing. The study has demonstrated the impact health professionals play in Survivalising, exemplified by participants' sense of self-belief being increased when respect and appropriate support was provided. These individuals were subsequently able to move forward and reach the process of healing (see Section 5.6). Additionally, study participants who had bottomed-out, and were especially vulnerable, described how effective interactions with health professionals enabled them to increase their understanding of TB. With the increase in knowledge, individuals felt better able to address the challenges of adhering to TB treatment and were able to move towards healing.

[24] Developed with consultation from the Health Protection Agency.

Table 5: Survivalising – Themes, Context, Practice and Care

Theory	Zoning Out Day to day	Bottoming Out Acute crisis	Self Realisation Clarity, reflection and acceptance	Healing Picking up the pieces
Narrative themes	*"Drugs helped me to forget about reality. I mean when I was half-sober it was horrible. I was scared, cold, hungry and tired. I couldn't sleep in case someone crept up on me. It wasn't nice"* ***(28 year old female, sofa surfer)*** *"it's jus that's the circle, that's all there is in life and fighting getting drunk, nuisance, getting arrested, and drinking and piping that's all there is all day long"* ***(42 year old female, temporary accommodation)*** *I didn't want to face my responsibility, was trying to get high to get away from everything"* ***(41 year old male, temporary bed-sit)*** *"the longer you're on the street the more tried and run down you get" (40 year old male, hostel user)*	*"When I came here [hospital] with TB they gave me three weeks to live and it really freaked me out"* ***(28 year old female, sofa surfer)*** *"I was told by the doctor that I had TB, I didn't think for one minute I had TB. I was shocked, I was scared and I feel alone, felt alarmed and there's no one there beside me, so I was really in deep thoughts"* ***(42 year old female, temporary accommodation)*** *"some doctor told me I have TB…nightmare…I am sad, I am cry not in the eye, my heart cry"* ***(49 year old male, rough sleeper)***	*"It was multiple habits…heroin, crack cocaine, and alcohol and I couldn't keep up with it. I had enough of it, and I put my hands out…I need help. That's when I went to the primary care unit"* ***(38-year-old male, hostel user).*** *"I got a second chance, so I have to try and do it properly this time"* ***(28 year old female, sofa surfer)*** *"I thought, for the first time in my life, my life meant something to me in a long time"* ***(42 year old female, temporary accommodation)*** *"…It's only when you get something, isn't it and then you realise the seriousness of it"* ***(41 year old male, hostel user)***	*"My treatment is the most important thing to me. I'm not just on treatment for TB; I'm on treatment for other things. I'm trying to sort my life out now. I'm just sorting out my health. That is my priority at the moment, and then I can think about other things once I'm better"* ***(31 year old female, hostel user)*** *"I feel like my priorities have changed"* ***(40 year old male, hostel user)*** *"I've got something to focus on, which is good, like coming here three day's a week, it's giving me something to do [DOT]"* ***(52 year old male, squatter)*** *"I'm aware of what medication I'm taking and how I should be taking them. I'm always egger to know how I'm progressing and to learn…"* ***(42 year old male, hostel user)***

Table 5: Survivalising – Themes, Context, Practice and Care

Theory	Zoning Out Day to day	Bottoming Out Acute crisis	Self Realisation Clarity, reflection and acceptance	Healing Picking up the pieces
TB context	▪ Increased risk of infection ▪ Increased risk of progression ▪ Clinical symptoms masked by lifestyle ▪ Chaotic lifestyle ▪ Criminal behaviour ▪ Poor service access ▪ Diagnosis = denial ▪ Poor adherence and LFU[25] & death	▪ Acutely physically ill ▪ Depression / suicide / acopic ▪ Delay to presentation ▪ Stigma of TB ▪ Acute fear of death ▪ Self loathing ▪ Diagnosis = Shock ▪ Poor adherence and LFU & death	▪ Seeking help ▪ Desire to live ▪ Life could be better ▪ Diagnosis = acceptance ▪ Treatment adherence	▪ Self control ▪ Taking treatment ▪ Dealing with other issues – drugs alcohol mental health housing etc. ▪ Rebuilding broken relationships ▪ Thinking about the future ▪ Improved self esteem ▪ Treatment adherence
Practice and care	▪ Outreach ▪ Active case finding ▪ Promoting awareness ▪ Recognising the clients state ▪ Risk assessment and referral ▪ Safe environment ▪ Continuous assessment, analysis and action	▪ Outreach ▪ Active case finding ▪ Engaging ▪ Building rapport ▪ Safe environment ▪ Recognising the clients state ▪ Continuous assessment, analysis and action	▪ Outreach ▪ Providing options - Rapidly pulling together a comprehensive/complementary care package ▪ Co-ordinating multidisciplinary care ▪ Setting goals ▪ Recognising the clients state ▪ Continuous assessment, analysis-action	▪ Outreach/follow-up ▪ Recognising the clients state ▪ Continuous assessment, analysis and action ▪ Measuring quality of care and outcomes ▪ Quality of life ▪ Supportive mechanisms in place

[25] Lost to Follow Up (LFU)

7.2.3 Implications & Recommendations for Policy

It is well documented that researchers can often immerse themselves in the technicalities of their study without considering their role in pursuing the wider policy implications (Philpott *et al* 2002). Therefore, it is important to consider the impact of the current study on policy.

The findings from this study illustrate the need for policy to better address the struggles participants face in their daily lives. An important element in addressing the social exclusion experienced by these individuals is to place TB service with an individualised package of care, specifically designed to meet the needs of homeless TB patients. Currently, TB centres provide very different services (Story *et al* 2004).

Policies need to support good practice. Good practice requires a multidisciplinary approach to services, with effective out-reach, health education, and early detection (Story *et al* 2004). One of the findings from this current study was that numerous individuals were not diagnosed with TB until it was at an advanced stage and were in a critical state of health. Implementing a policy of out-reach for all TB clinics could address this shortcoming. It is also important to improve access to a broader range of health and social care services. Finally, professionals that work directly with the homeless can be educated to identify the stages of Survivalising. Working with health professionals, these front-line social workers can help guide individuals with TB toward appropriate support services and assist them to move toward healing.

In an effort to increase the likelihood of this study having an impact on policy, the researcher approached policy makers within Government. The effort was rewarded when the researcher was selected to disseminate at the Annual Presentations by Britain's Early-Stage Researchers at the House of Commons[26]. The event was the grand finale to the 2007 National Science & Engineering Week and Members of

[26] The Annual Presentations by Britain's Early-Stage Researchers at the House of Commons– *19/03/2006*

Parliament (MPs) attended the event. The researcher disseminated the research findings to MPs from both major parties (Labour and Conservative).

Following the House of Commons presentation, the Social Exclusion Section at the Mayors Office in City Hall invited the researcher to present the research findings to their department[27]. They have since contacted the researcher requesting support on homeless/TB matters in London.

7.3 Conclusion

The theory of Survivalising has significant implications for health professionals and policy makers and contributes to the existing body of literature through a new conceptualisation of our understanding of the homeless/TB phenomenon.

On a practical level, evidence from the study indicates that health professionals have an important role in the process of Survivalising. By recognising the different stages, health professionals can assist homeless individuals through the Survivalising process. Study results showed that some participants moved directly from zoning-out to self-realisation. This was linked to positive relationships with health professionals, founded upon respect and rapport, which increased homeless individual's sense of self-worth and led to improved adherence to TB treatment. The theory also provides a practical means for determining the appropriate treatment of the homeless individual and the disease they are infected with (TB). Sharing Survivalising with other professionals working on homeless issues can lead to a better package of care.

Policy makers can better address the problem of late TB diagnosis, which leads to some individuals developing advanced stage TB, through implementing an extended policy of out-reach for TB clinics. Ultimately, policies that provide access to a broad range of health and social care services are needed to improve the health and wellbeing of homeless people with TB.

[27] Mayors Office- City Hall – *05/04/2006*

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APPENDICES

Appendix A: Preamble

The following section presents the researcher's personal experiences of homelessness. During the research journey, the researcher developed insights, sometimes unexpected, in three inter-related domains: personal, professional and academic. Thus, the motivation for conducting this study was very much influenced by a number of factors which are described below.

Personal

Before I was born, my parents had adopted two children, who were both street kids[28] in Indonesia. Then, at the age of 22, I discovered that as a child my mother had experienced homelessness. It was when on holiday in Medan, Indonesia (my mother's birthplace), that she began to tell me about this experience. My mother pointed out a restaurant where she, her mother, father and sister would sleep at night.

In the late 1940s my Indonesian grandfather, who had trained in the Netherlands as a naval captain, returned to Medan with his Dutch wife having been offered a good job. They brought a house and began to raise a family there. However, after a serious fall from the boat involving a blow to his head causing memory loss, he could not work any longer. He lost his job and turned to alcohol. With no financial support network available, the family ended up on the streets of Medan. Today my mother rarely talks about that part of her life but it still affects her and, at the age of 53, she still finds it far too painful to discuss.

My interest in the issues of poverty and homelessness was broadened by regular and in-depth discussions with my father, an international social worker. Understanding his experiences also helped me to appreciate the issues of homelessness from a professional viewpoint.

[28] UNICEF's definition, cited by Scanlon *et al* (1998:1596), defines street kids/children as "Street based children who spend most days and nights on the street and are functionally without family support".

Professional

This knowledge was augmented while working as a nurse on an infectious disease unit in London where I became conscious of a particular homeless patient's inadequate care. He had been admitted with tuberculosis and had difficulties in taking his medication regularly. The staff at the unit appeared to lack knowledge of homelessness and how it could affect adherence to medication. During the patient's hospital stay, I also became aware that my knowledge was insufficient to meet his care needs. Although I had been personally exposed to some of the issues early on in my life, I knew little about what tuberculosis meant to homeless people or how to help them and it was obvious that other staff were also unaware.

I remained perplexed about this until the opportunity arose to undertake an extended literature review on the topic of tuberculosis in the homeless for my undergraduate project. It appeared to me that there was a connection between tuberculosis and homelessness. There were indications in the literature that tuberculosis was more common among the homeless, and that, although it is a curable disease, homeless people have complex social and medical problems that affect access to care and tuberculosis treatment completion. If so, this could develop into a serious public health problem, ultimately resulting in loss of life and a risk of outbreaks among the general public. However, a preliminary review of the literature indicated that there has been very little research in this area.

Academic

I wanted to make a scientific contribution to the management of tuberculosis, and had initially assumed that a quantitative study would be the best approach to influence policy and practice. However, the literature revealed that the majority of studies of tuberculosis, which were based on medical treatment, were quantitative in design and did not focus on the experience of individual sufferers. Very little was known about problems of coping with tuberculosis and its treatment, particularly among vulnerable groups. It became apparent that a quantitative study would not be productive because research was needed into the way that vulnerable groups dealt with their treatment and their perspective on it. This motivated me to address the research problem through a PhD, which I began in January 2003.

During the first year of my PhD, I studied the literature and joined the project team of the Pan-London tuberculosis study. This was a profiling survey that sought to map the demography of tuberculosis in London. The study confirmed my early impression that Tuberculosis (TB) is a problem among certain vulnerable groups in London. The homeless were one such group. At this point, my studies were interrupted by a catastrophe.

On Boxing Day 2004, an earthquake, measuring 9.0 on the Richter Scale struck the island of Sumatra. Over half of the mortality caused by the tsunami occurred in Aceh (North Sumatra): 128,645 people were killed; 37,063 missing and presumed dead and more than 400,000 people were displaced. I watched the news and, like many, was deeply affected by the events that began to unfold. I left London on 1 January 2005 and arrived in Jakarta, the capital of Indonesia, the following day. I then travelled to Aceh where I worked as a nurse for three months with various non-governmental organisations, and a further three months with the United Nations Children's Fund (UNICEF). As soon as I arrived in Aceh, I became involved in treating homeless people who were living in overcrowded and unsanitary conditions. I witnessed the effect of these conditions on their health, for example respiratory infections and scabies. Psychosomatic conditions caused by the emotional trauma were also common, for example locked jaw, inability to speak or to walk.

My time helping in Indonesia gave me plenty of opportunity to contemplate the direction and nature of my studies. I had become increasingly aware of similarities in the experience of homelessness in Aceh and in London. Both groups were vulnerable to a range of health problems, including acute respiratory infections, acute diarrhoea, mental health issues, tuberculosis, scabies and other skin conditions. I became acutely aware of the need to empower this vulnerable group, firstly by listening to them.

Appendix B: Pan-London TB Study

Appendix C: Survey form used for the Pan London TB Study

London TB Case Load Profiling Outcome Form
July 1st 2004

Information for completion

This follow-up form aims to capture TB treatment outcomes and management issues for patients included in the London TB Case Load Profile 1st July 2003. The form is unique to a named patient treated by your service. The Centre Code and Serial Number at the foot of this form corresponds to a named patient on the list you compiled last year. The patients Age Group, Sex and Treatment Start Date has been pre-printed on the form to make sure that the correct patient is identified.

Please complete the form using your knowledge and local records of the patient. If you are in any doubt about how to interpret a question on this form please do not hesitate to contact either:-

- Your Sector Lead TB Nurse
- Maggie (the nurse appointed as co-ordinator Tel)
- (last years co-ordinator Tel)
- or (Tel)

Maggie will arrange for the completed forms to be collected.

The questions are designed to reflect the complex management, workload and resource implications for the service. This is NOT a tool to assess individual performance. Information from this form will be combined with the data captured in 2003 and will be fed back to you directly. The London TB Nurses Network retain the final say in how this information will be used to inform service development. Your contribution to this project is invaluable and will make a real difference to TB control and patient care in London.

Any additional comments relevant to the care of this patient:

Completed by: Date completed: / /

Case details: Age Group 30 - 39 started treatment on: 18/06/2003

Gender F

Case UI Centre UI

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1.0 Treatment diary

If treatment duration >12 months please contact study coordinator for additional form

	Treatment Month											
(Cross ALL relevant boxes)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
Self Supervised	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
DOT	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Took TB-meds as planned	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Suspect TB-meds intermittent (<80% of prescribed dose)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Took TB-meds intermittently (<80% of prescribed dose)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Took no TB-meds this month	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Lost to F/U (missed prescription & No service contact this month)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Home, community or prison visit (one or more this month)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Prison or remand on any day during this month	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Treatment withdrawn / modified due to side effects	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Treatment withdrawn due to poor compliance	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Treatment restarted following >2weeks interruption	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Missed Out Patient Follow-Up	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
(Cross ONE box ONLY)												
Care transferred out * (see 1.4)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Case NOT TB - Rx stopped	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

1.1 Date last dose of this treatment episode ☐☐ / ☐☐ / ☐☐☐☐

1.2 Status at end of TB clinical follow up or last contact with TB service or as of 1st July 2004 **(cross ONE)**

- ☐ Discharged
- ☐ Still under care for TB treatment
- ☐ Still under care for TB review
- ☐ Lost to follow up (with <6 months treatment)
- ☐ Patient died - TB related
- ☐ Patient died - NOT TB related
- ☐ Patient died - Unknown if TB related
- ☐ Status unknown

1.3 Please give date of death **(month and year if day unknown)** ☐☐ / ☐☐ / ☐☐☐☐

***1.4** Where was care transferred out? (hospital or country) ☐ Cross if unknown ☐

1.5 DOT **(cross ANY)**

- ☐ No DOT
- ☐ Clinic based DOT
- ☐ Community based DOT
- ☐ More than one location DOT
- ☐ Daily DOT
- ☐ 3 x weekly DOT
- ☐ DOT TB nurse supervised
- ☐ DOT allied prof. supervised
- ☐ DOT friend / family supervised

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1.6 Episodes of hospital admission while on treatment. If > 5 episodes of hospital admission please contact study co-ordinator

Episode	Date admitted	Date discharged	Clinical reason	Social / compliance reason	Discharge delayed for social reasons	Public Health Act compulsory detention
1	/ /	/ /	☐	☐	☐	☐
2	/ /	/ /	☐	☐	☐	☐
3	/ /	/ /	☐	☐	☐	☐
4	/ /	/ /	☐	☐	☐	☐
5	/ /	/ /	☐	☐	☐	☐

1.7 TB clinical management at end of treatment or last known **(cross ONE)**

- ☐ TB TEAM ONLY
- ☐ SHARED TB (> ONE TB TEAM)
- ☐ JOINT TB / HIV (Same clinic)
- ☐ SHARED TB / HIV (Separate clinics)
- ☐ HIV ONLY
- ☐ SHARED or JOINT TB/PAED
- ☐ PAED ONLY
- ☐ SHARED TB/GP
- ☐ GP ONLY
- ☐ OTHER

1.8 Allied services Contacted in the course of managing this case **(cross ANY)**

	Yes ever	Yes for DOT		Yes ever	Yes for DOT
Other TB Service	☐	☐	General Practitioner	☐	☐
Community nurses (district/HV's/School Nurses)	☐	☐	Alchohol / drug workers	☐	☐
Community mental health teams	☐	☐	Housing / homeless workers	☐	☐
Social workers	☐	☐	CCDC	☐	☐
Hostel staff - inc. key workers	☐	☐	Courts / police / prison staff	☐	☐
Pharmacist	☐	☐	Asylum/immigration	☐	☐

1.9 Was / is the patient part of the INHR outbreak of TB in London? ☐ No ☐ Yes ☐ Unknown

1.10 Was Ethambutol included in the initiation phase at start of treatment? ☐ No ☐ Yes ☐ No culture ☐ Unknown

1.11 Was the patient resistant to any 1st line drugs at start of treatment? ☐ No ☐ Yes ☐ No culture ☐ Unknown

If yes please tick all drugs that were resistant at start of treatment ☐ INH ☐ RIF ☐ Other ☐ Unknown ☐ EMB ☐ PZA

1.12 Did a new drug resistance develop during this treatment episode? ☐ No ☐ Yes ☐ No culture ☐ Unknown

If yes please tick all drugs to which the patient became resistant to this treatment episode ☐ INH ☐ RIF ☐ Other ☐ Unknown ☐ EMB ☐ PZA

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1.0 Treatment diary

If treatment duration >12 months please contact study coordinator for additional form

	Treatment Month											
(Cross ALL relevant boxes)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
Self Supervised	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
DOT	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Took TB-meds as planned	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Suspect TB-meds intermittent (<80% of prescribed dose)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Took TB-meds intermittently (<80% of prescribed dose)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Took no TB-meds this month	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Lost to F/U (missed prescription & No service contact this month)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Home, community or prison visit (one or more this month)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Prison or remand on any day during this month	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Treatment withdrawn / modified due to side effects	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Treatment withdrawn due to poor compliance	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Treatment restarted following >2weeks interruption	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Missed Out Patient Follow-Up	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
(Cross ONE box ONLY)												
Care transferred out * (see 1.4)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Case NOT TB - Rx stopped	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

1.1 Date last dose of this treatment episode ☐☐ / ☐☐ / ☐☐☐☐

1.2 Status at end of TB clinical follow up or last contact with TB service or as of 1st July 2004 **(cross ONE)**

- ☐ Discharged
- ☐ Still under care for TB treatment
- ☐ Still under care for TB review
- ☐ Lost to follow up (with <6 months treatment)
- ☐ Patient died - TB related
- ☐ Patient died - NOT TB related
- ☐ Patient died - Unknown if TB related
- ☐ Status unknown

1.3 Please give date of death **(month and year if day unknown)** ☐☐ / ☐☐ / ☐☐☐☐

***1.4** Where was care transferred out? (hospital or country) ☐ Cross if unknown ☐

1.5 DOT **(cross ANY)**

- ☐ No DOT
- ☐ Clinic based DOT
- ☐ Community based DOT
- ☐ More than one location DOT
- ☐ Daily DOT
- ☐ 3 x weekly DOT
- ☐ DOT TB nurse supervised
- ☐ DOT allied prof. supervised
- ☐ DOT friend / family supervised

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Appendix D: MREC Ethics approval letter

NHS
Royal Free Hospital & Medical School
Local Research Ethics Committee
Royal Free Hospital
Ground Floor
Pond Street
London
NW3 2QG

Telephone: 0207 830 2746
Facsimile: 0207 830 2961

02 December 2005

Miss Magdalena Verheyen
PhD Student
Research Centre for Health Studies
Buckinghamshire Chilterns University College
Newland Park, Gorelands Lane
Chalfont St Giles, Buckinghamshire
HP8 4AD

Dear Miss Verheyen

Full title of study: **A grounded theory study exploring what having tuberculosis means to homeless people and how this impacts on their opportunities to complete treatment**

REC reference number: **05/Q0501/174**

Thank you for your letter of 10 November 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair Dr Michael Pegg

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA. There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application	5.0	05 October 2005
Investigator CV		03 October 2005
Protocol	1	01 September 2005
Covering Letter		20 September 2005
Letter from Sponsor		03 October 2005
Compensation Arrangements		05 October 2005
Interview Schedules/Topic Guides		12 September 2005
Advertisement		09 September 2005
GP/Consultant Information Sheets	1	14 September 2005
Participant Information Sheet		02 October 2005
Participant Information Sheet	2	10 November 2005
Participant Consent Form	2	10 November 2005
Participant Consent Form		14 September 2005
Response to Request for Further Information		10 November 2005
Letter from funder		28 May 2005

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q0501/174	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

M.S Pegg

Chair

Email: rosemary.brown@royalfree.nhs.uk

Enclosures:

Standard approval conditions [SL-AC1 for CTIMPs, SL-AC2 for other studies]

SF1 list of approved sites

Appendix E: Informed Consent Form

Buckinghamshire Chilterns
UNIVERSITY COLLEGE

Centre Number:
Study Reference Number: 05/Q0501/174

INFORMED CONSENT FORM

Title of Project: Exploring what having tuberculosis is like for homeless people and how it affects their lives.

Name of Researcher: Maggie Verheyen **Please initial box**

1. I confirm that I have read and understand the information sheet dated 10 November 2005 (version 2) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that staff at *clinic name* will need to look at my medical records and I give permission for this. ☐
4. I understand that the interview will be tape recorded and I give permission for this. ☐
5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature
Researcher	Date	Signature

Thank you

Appendix F: Participant Information Sheet

Buckinghamshire Chilterns
UNIVERSITY COLLEGE

LONDON HOMELESS STUDY- INFORMATION SHEET

1. Study title

A study exploring what having tuberculosis is like for homeless people and how it affects their lives

2. Invitation

You are invited to take part in this study but, before you decide, please take time to read the following information carefully and discuss it with others if you wish. Take time to decide whether or not you are willing to take part and please ask if you would like more information.
Thank you for reading this.

3. What is the purpose of the study?

We know little about the issues and problems that homelessness people with tuberculosis face in their daily lives. The study aims to increase our understanding of how homeless people cope with their lives and how this effects their TB treatment.

4. Why have I been chosen?

You have been asked to take part because you are homeless and have TB. Around 30 other people will also take part in the study from other clinics in London.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you agree to take part you will be asked to sign a consent form. This form says that, even though you agreed to take part, you are still free to withdraw at any time without giving a reason. Whatever you decide, and even if you change your mind, this will not affect your current or future health care in any way.

6. What will I be asked to do?

If you agree to help with this study, you will be asked to take part in a tape recorded interview with me, Maggie Verheyen. I will ask you to talk about the things you feel are important about homelessness and TB. The discussion will take about an hour, but the more you can tell me the better, so I will keep listening as long as you keep talking. I would like to have the discussion in a private room at your clinic.

I will be happy to offer you £10 for your time and any expenses you have incurred, e.g. travel.

After the discussion I will write down everything that you have said. I will then come back to the clinic to show you what I have written and, if you disagree with any of it, I will change it.

7. What are the possible disadvantages of taking part?

The discussion will take up about an hour of your time. I will not pry into sensitive areas, but it will be up to you what you tell me and we can stop the interview at any time you wish.

8. What are the possible benefits of taking part?

Although there will be no immediate benefits to helping with this study, I do hope that the findings will result in improvements in care for homeless people with TB.

9. Will my taking part in this study be kept confidential?

Yes, special care will be taken to ensure that information about you is kept confidential. All data will be collected and stored in accordance with the Data Protection Act 1998. However, if you choose to disclose a serious health or social issue, I might have an obligation to refer this matter to an appropriate professional.

Any information about you that leaves the clinic will have your name removed so that you cannot be recognised. The tapes will be kept in a locked drawer in a secure university building and I will be the only person who will listen to them. Any names or place names that you mention will be changed and no information given will be used in a way that would identify you. All information from the interview will be stored for five years, after which it will be destroyed.

If you agree, I will send your general practitioner a courtesy letter, just to tell them you are helping with the study.

10. What will happen to the results of the research study?

When the study is complete, around November 2006, I will publish my findings in a professional journal and a homeless publication in order that as many people as possible can benefit from what I have learned. I will come back to the clinic and talk to you and others about what I have found. I promise to safeguard your confidentiality and privacy so that you will not be identified in any way in these publications or talks.

11. Who is organising and funding the research?

I have been assisted financially by a university bursary and by help from the Worshipful Company of Curriers.

12. Who has reviewed the study?

This study has been approved by Royal Free Hospital and Medical School Research Ethics Committee.

13. Contact for Further Information

If you would like to discuss anything about the project, before or after our meeting, please call: Maggie Verheyen on 01494 522141 Ext. 2203.

Thank You

Appendix G: Theoretical Coding Families

"Theoretical codes conceptualize how the substantive codes may relate to each other as concepts to be integrated into a theory. They like substantive codes, are emergent; they weave the fractured story back together again. Without substantive codes, they are empty abstractions." (Glaser 1978:72)

"Without substantive codes, theoretical codes are empty abstractions. But substantive codes could be related without theoretical codes, but the result is usually confused, unclear theoretically, and/or typically connected by descriptive topics but going nowhere theoretically" (Glaser 1998:164).

Families	**Examples** (Glaser 1978:74-82)
The Six C's	Causes (sources, reasons, explanations, accountings or anticipated consequences), Context or Ambiance, Contingencies, Consequences (outcomes, efforts, functions, predictions, anticipated/ unanticipated), Covariances, Conditions or Qualifiers.
Process	Stage, Staging, Phases, Phasing, Progressions, Passages, Gradation, Transitions, Steps, Ranks, Careers, Ordering, Trajectories, Chains, Sequencing, Temporaling, Shaping, Cycling.
Degree	Limit, Range, Intensity, Extent, Amount, Polarity, Extreme, Boundary, Rank, Grades, Continuum, Probability, Possibility, Level, Cutting Points, Critical Juncture, Statistical Average (mean, medium, mode), Deviation, Exemplar, Modicum, Full, Partial, Almost, Half.
Dimension	Dimensions, Elements, Divisions, Piece of, Properties of, Facet, Slice, Sector, Portion, Segment, Part, Aspect, Section.
Type	Type, Form, Kinds, Styles, Classes, Genre.
Strategy	Strategies, Tactics, Mechanisms, Managed, Way, Manipulation, Manoeuvring, Dealing with, Handling, Techniques, Ploys, Means, Goal, Arrangements, Dominating, Positioning.
Interactive	Mutual Effects, Reciprocity, Mutual Trajectory, Mutual Dependency, Interdependence, Interaction of effects, Covariance [GLASER78], Face to Face Interactions, Self-indications, Delayed-interaction [GLASER98, Symbolic Interaction].
Identity-Self	Self-image, Self-concept, Self-worth, Self-evaluation, Identity, Social worth, Self-realization, Transformation of self, Conversions of identity.

Cutting Point	Boundary, Critical juncture, Cutting point, Turning point, Benchmark, Division, Cleavage, Scales, In-out, Intra-extra, Tolerance levels, Dichotomy, Trichotomy, Polychotomy, Deviance, Point of no return.
Means-goal	End, Purpose, Goal, Anticipated consequences, Products.
Cultural	Social norms, Social values, Social belief, Social Sentiments.
Consensus	Clusters, Agreements, Contracts, Definitions of Situation, Uniformities, Opinions, Conflict, Disconcensus, Differential perception, Cooperation, Homogeneity-heterogeneity, Conformity, Non conformity, Mutual expectation.
Mainline	Social control, Recruitment, Socialization, Stratification, Status passage, Social organization, Social order, Social interaction, Social mobility.
Theoretical	Parsimony, Scope, Integration, Density, Conceptual level, Relationship to data, Relationship to other theory, Clarity, Fit, Relevance, Modifiability, Utility, Condensibility, Inductive-Deductive balance and interfeeding, degree of, Multivariate structure, Use of theoretical codes, Interpretive, Explanatory, Predictive Power.
Ordering or Elaboration	Structural Ordering (unit size of: organization, division...), Temporal Ordering (A-->B-->C), Conceptual Ordering (Achievement Orientation, Institutional Goal, Organizational value, Personal Motivation).
Unit	Collective, Group, Nation, Organization, Aggregate, Situation, Context, Arena, Social world, Behaviour pattern, Territorial Units, Society, Family.
Reading	Concepts, Problems, Hypotheses.
Models	Linear model, Property Space.

Families	**Examples** (Glaser 1998:170-175)
Basics	Basic Social Structural Process, Basic Social Structural Condition (shifts, semesters, quarters, fiscal), Basic Social Psychological Process (teaching, child rearing, learning curves, becoming, education, grieving, maturing), Basic Psychological Process (identity development, character formation, loving, unconscious agendas)
Paired Opposite	Ingroup-Outgroup (in-out), Manifest-Latent, Explicit-Tant, Figure-Ground, Normative-Comparative, Reduction-Substruction, Induction-Deduction, Generative-Verificational, Unit-Concept.
Representation	Descriptive, Proscriptive, Prescriptive, Evaluative, Sentimental. Properlining, Interpreting, Vauging, Base-lining, Conceptualizing.
Scale	Likert Scales, Guttman Scales, Cumulative Scales, Random Walk Scale, Funneling Down, Scaling Down.
Structural Functional	Authority Structure, Reference Groups, Role Sets, Status Sets.
Boundary	Confidence Limit, Tolerance Zone, Front Line.
Unit Identity	Professions.
Average	Mean, Median, Mode, Confidence Limit, Tolerance Zones.

Appendix H: 23 Memoing Rules: What to do

1. Each memo needs to be introduced by a title or caption which is the category or property that the memo is about (thus in the future the memo can be readily sorted for this concept).
2. Any other category or property which appears in the memo should be highlighted (so the memo could be sorted for this concept also).
3. If two categories or their properties appear in the memo, the relationship between the two should be discussed and perhaps categorized (the hypothesis) or highlighted (so this hypothesis could be sorted for also).
4. Memos should by typed up, with 2 copies (so one set can be easily scissored up, taped in new combinations and sorted without losing an original).
5. It is better to keep memos separate of transcribed data (difficulty in cutting it up)
6. Be prepared to sort memos wherever they may fall.
7. At the beginning of the study, the principle source of memos is the constant comparative process, comparing indicator to indicator, then indicator to concept.
8. After this the sources snowball into every stage of the GT process as comparisons become plentiful.
9. Memos generate new memos and rememos or rewriting memos.
10. Reading in the field, which yields more data, generates memos.
11. In the latter stages of coding when memoing is at a peak, refer to the list of emergent codes for possible relationships I have missed or not thought of. Thus while the memo stage begins during the joint collection, coding, and analyzing of data, and peaks as coding saturates, it is never over.
12. WHEN WRITING MEMOS TALK CONCEPTUALLY ABOUT THE SUBSTANTIVE CODES AS THEY ARE THEORETICALLY CODED: DO NOT TALK OF PEOPLE (this maintains the conceptual level as relationships among concepts, it gives me practice for the final write-up. People occur in the references to indicators, but the analysis is about conceptually generated patterns which people engage in, not about the people per se.

13. Keep memos and data separate.
14. One idea at a time to prevent confusion.
15. All memos should be referenced to field notes from where they emerged (so the analyst can check grounding).
16. Always interrupt coding or data recording for writing a memo, when an idea occurs, so the idea is not lost.
17. Set aside a block of time for coding and memoing when I'm not allowed to be disturbed
18. Do not be afraid to modify memos as growth and realization occurs. It can lead to a better memo.
19. Keep a list of the emergent codes handy, to check at the peak stage of memoing for possible relationships missed or not thought of.
20. If too many memos on different codes seem the same, compare codes or their dimensions for differences that are missed between the two codes. If they are still the same, collapse the twp into one code.
21. Run the memos open as long as resources allow to develop the rich diversity that they afford for doing various pieces out of them.
22. In memos indicate "Saturation" when I think I have saturated the category.
23. I will have my own personal recipe the above is just Glasian advice!