

**OCCUPATIONAL ADAPTATION: THE EXPERIENCES OF  
ADULT PATIENTS WITH MDR- TB WHO UNDERGO  
LONG- TERM HOSPITALISATION**

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**A mini-thesis submitted in partial fulfilment of the requirements for the  
degree of Magister Scientae in the Department of Occupational Therapy,**

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## **KEY WORDS**

Health and Well- Being

Multi- Drug Resistant Tuberculosis

Long- term Hospitalisation

Occupation

Occupational Adaptation

Occupational Competence

Occupational Identity

Occupational Risk Factors

Phenomenology

Qualitative research



## ACRONYMS

DOTS:	Directly Observed Treatment Strategy
ICCD	The International Center for Clubhouse Development
MDR- TB:	Multi- Drug Resistant Tuberculosis
MSF:	Medecins Sans Frontiers
OT:	Occupational Therapy
TB:	Tuberculosis
WFOT:	World Federation of Occupational Therapy
WHO:	World Health Organisation
XDR- TB:	Extensively Drug Resistant Tuberculosis



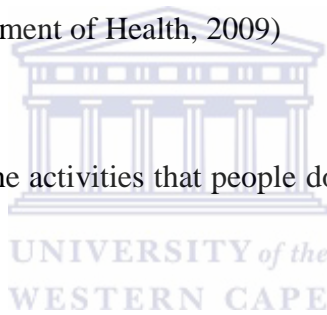
## **Definition of Terms**

*Health and Well- Being:* a state of complete physical, mental and social well-being and not merely the absence of disease (WHO, 1948).

*Multi- Drug Resistant Tuberculosis:* diagnosis given to patients who have TB that is caused by bacteria that are resistant to isoniazid and rifampicin, the two most effective anti-TB drugs (WHO, 2010).

*Long- term Hospitalisation:* hospitalization of MDR TB patients for a period of at least 6 months (Department of Health, 2009)

*Occupation:* refers to the activities that people do to bring meaning and purpose to life (WFOT, 2004).



*Occupational Adaptation:* a process through which the person and the environment interact when the person is faced with a challenge that calls for an occupational response (Schkade and Schultz, 1992).

*Occupational Competence:* refers to the degree to which one sustains a pattern of occupations that reflects one's occupational identity (Kielhofner, 2007)

*Occupational Identity:* refers to a composite definition of the self, which includes one's roles, values, self- concept and personal goals (Kielhofner, 2007).

*Occupational Risk Factors:* occur as a result of doing too much or too little i.e. occupational imbalance, finding little meaning and purpose in doing i.e. occupational alienation and lacking opportunities to strive towards becoming i.e. occupational deprivation (Wilcock, 1998).

*Phenomenology:* a theory that perceives meaning in the structure and essence of an experience of a particular phenomenon by certain people (Patton, 1990).

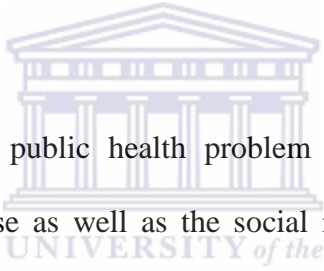


## ABSTRACT

# **OCCUPATIONAL ADAPTATION: THE EXPERIENCES OF ADULT PATIENTS WITH MDR- TB WHO UNDERGO LONG-TERM HOSPITALISATION**

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TB is a multi- faceted public health problem spurred on by the biological progression of the disease as well as the social issues associated with it. The treatment of TB is however primarily driven by the medical model where the focus is on the disease and not on a holistic view of the patient. Occupational therapy is a profession concerned with the use of occupation in the promotion of health and well being through the facilitation of the process of occupational adaptation. There is however a paucity of literature pertaining to the role that occupational therapy could play within the TB context. The aim of this study was to explore how adults with MDR- TB who undergo long-term hospitalisation at a hospital in the Western Cape experience occupational adaptation. The objectives of the study were to explore how the participants perceive their occupational identity, to explore the meaning and purpose the participants assign to their occupational engagement and to explore the how the participants perceive their occupational competence. The interpretive research paradigm employing a

phenomenological qualitative research approach was utilized in this study. Purposive sampling was used to select four participants based on specific selection criteria. The data gathering methods utilized included diaries, semi-structured interviews, participant observation and a focus group. Photographs taken by the researcher for the purpose of participant observation were used to elicit a rich, in depth response from the participants during the focus group discussion. All data was analysed through thematic content analysis. The study findings highlighted that the participants viewed themselves as occupational beings and that they valued the role that occupational engagement played in facilitating their occupational competence and ultimately their ability to adapt to long- term hospitalisation. The environmental demands and constraints that they experienced however infringed their engagement in meaningful occupation and hampered their ability to achieve occupational competence. It was recommended that the hospital adopt an integrative intervention approach to the management of MDR- TB patients that include principles of psychosocial rehabilitation and occupational enrichment to address occupational risk factors and institutionalisation.

November 2011

**DECLARATION**

I, NOUSHEENA FIRFIREY, hereby declare that *Occupational Adaptation: The experiences of adult patients with MDR- TB who undergo long- term hospitalisation*, is my own original work, that it has not been submitted for another degree in this or any other university, and that all sources I have used or quoted have been indicated and acknowledged as complete references.

**FULL NAME:** .....

**SIGNATURE:** .....

**DATE:** .....





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Hospital Management,

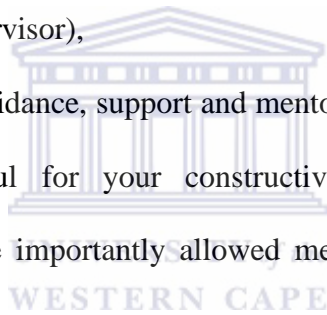
Thank you for granting me permission to conduct the study at the hospital.

Participants,

To all of you who participated in this study, I would like to thank you for so willingly sharing your experiences with me. This research would not have been possible without your invaluable contributions.

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I am grateful for your guidance, support and mentorship throughout this process. I am particularly thankful for your constructive criticism which constantly challenged me but more importantly allowed me to grow and explore my full potential as a researcher.



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Thank you for supporting me throughout this process and for always encouraging me to persevere and attain my goals.

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# CHAPTER 1

## INTRODUCTION

### 1.1 BACKGROUND

Tuberculosis (TB) is a multi-faceted public health problem. On the one hand, there is the biological progression of the disease, and on the other hand there are the social issues associated with it. According to the World Health Organization (WHO, 2007) TB is the second leading cause of death resulting from infectious diseases in the world today. South Africa is listed as one of 22 high burden TB countries with the fifth highest number of notified TB cases in the world (Grimwood, Almeleh, Hausler and Hassan, 2006). The WHO (2003) states that TB is a communicable disease, highlighting poor adherence to TB treatment as a major barrier to global TB control as it increases the risks of morbidity, mortality and drug resistance at individual and community levels.

Over the last few years multi drug resistant TB (MDR TB) and extensively drug resistant TB (XDR TB) have become a serious concern. In 2008 an estimated 440 000 cases of MDR TB emerged globally resulting in approximately 150 000 deaths (WHO, 2010). MDR TB is caused by bacteria that are resistant to isoniazid and rifampicin, the two most effective anti-TB drugs (WHO, 2010). According to Thaver and Ogunbanjo (2006) factors such as poor treatment

adherence, poverty as well as HIV co- infection have all contributed to the emergence of MDR and XDR TB. The main reason for poor treatment adherence is low socio- economic status. The length of the treatment period also emerged as a contributory factor to the temptation to discontinue TB therapy impacting negatively on treatment outcomes (Matabesi & Booysen, 2004; Portwig & Couper, 2006). Moreover, Matabesi and Booysen (2004) and Portwig and Couper (2006) argue that TB is a stigmatised disease with one of the major problems for people suffering from TB being a lack of support from health workers, family and friends.

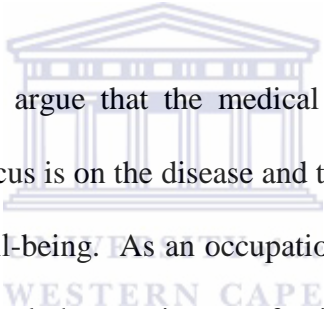
According to the South African Department of Health (2008), MDR TB patients should be hospitalised for at least the first 6 months of their treatment. Medecins Sans Frontiers (MSF, 2009) however argues that there is little evidence to prove that long term hospitalisation improves adherence or that it prevents transmission of the disease as specialised hospitals are situated far from the homes of the patients leading to feelings of isolation and neglect. These factors ultimately have a negative effect on adherence.

## **1.2 RATIONALE FOR THE STUDY**

This study emanated from my reflections on the problem of poor treatment outcomes of MDR TB patients in South Africa. As an occupational therapist at a TB hospital in the Western Cape where primarily adults with drug resistant TB are hospitalised I observed that patients are often isolated from their families and communities during the period of hospitalisation and that their occupational roles such as that of parent, caregiver, breadwinner and student are compromised.



Many patients have to forfeit their employment as a result of hospitalisation which sacrifices the sole income for their families. In addition, the patients are faced with the stigma of being hospitalised and are often ostracised by their communities and in some cases even by their families. In reflecting on the problem of poor treatment outcomes I came to the conclusion that some patients become de-motivated and as a result interrupt their treatment and simply refuse intervention such as occupational therapy, resulting in a negative impact on their overall treatment success. This further led me to reflect on the role that occupational therapy could play in addressing poor treatment outcomes in MDR TB patients.



Swartz and Dick (2002) argue that the medical model still largely drives the treatment of TB as the focus is on the disease and the effects thereof as opposed to the patients' sense of well-being. As an occupational therapist I agree with these two authors. Occupational therapy is a profession concerned with the use of occupation to promote a person's health and well-being (WFOT, 2004). Townsend (1997) asserts that occupations have the potential to emancipate, empower and transform individuals within their environments thus allowing them to overcome barriers and to pursue aims such as health and happiness. Occupations thus have the ability to empower and liberate people thereby boosting their morale and improving their well-being. She argues that occupation is crucial in addressing health problems as it is comprised of four key features of occupation namely learning which involves engaging in a process of planning, doing and reflecting; organising time and place which provides structure; discovering meaning which involves reflection on experiences, and exercising

choice and control which allows for decision making and exerting control over one's life and environment.

According to Wilcock (1998) meaningful occupation can provide ways for people to exercise and develop their mental, physical, social and spiritual capacities. This process is referred to as occupational adaptation and is based on the assumption that every individual has a strong internal desire to engage in meaningful occupation with the purpose of striving towards competence or self-actualisation (Schkade and Schults, 1992 cited in Klinger, 2005). It is Kielhofner's (2007) view that occupational adaptation encompasses two components namely occupational identity and occupational competence. Occupational identity refers to a composite definition of the self which includes one's roles, values, self concept and personal goals (Kielhofner 2007). For Kielhofner (1995), competence is achieved when an individual encounters positive experiences, which support the desire to explore, master and fulfil environmental demands. He refers to this as an adaptive cycle that allows the person's choices, routines and skills to promote positive behaviours which lead to increased organisation. In contrast, inadequate adaptation leads to dysfunction which Kielhofner refers to as a maladaptive cycle. He states that dysfunction occurs when a person experiences repeated disorganisation, poor performance and anticipation of future failure Kielhofner (1995). This implies that poor choices, poorly organised routines and deficient skills lead to increased disorganisation of a person's life.

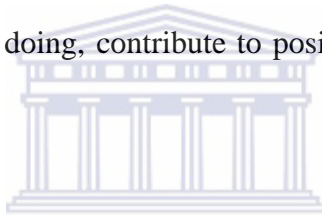
Farnworth and Muñoz (2009) assert that the occupational therapy profession regards meaningful, productive, freely chosen occupations as a means through which people are able to preserve their physical, social and mental health. Likewise, Klinger (2005) states that through occupational therapy intervention an occupational therapist may facilitate occupational adaptation within individuals so that competence can be achieved. For this reason, occupational therapists are concerned with working with people to re- orchestrate their occupational lives and to develop their occupational performance to a satisfactory level as determined by the clients' subjective experiences of their occupations (Doble and Santha 2008).

Hence, in reflecting on the role of occupational therapy in addressing poor treatment outcomes of MDR TB patients, I concluded that it is important to understand how long- term hospitalisation influences their occupational adaptation as this understanding would in turn facilitate an understanding of the patients' occupational needs. I further concluded that an understanding of the patients' occupational needs could guide the development of appropriate occupational therapy intervention strategies that would address their occupational needs and motivate them to engage in meaningful occupation with the purpose of facilitating occupational adaptation. The purpose of this study is therefore to generate an understanding of how MDR- TB patients who undergo long-term hospitalisation experience occupational adaptation from their perspective. This understanding is necessary in order to develop interventions that will enhance satisfactory occupational adaptation of TB patients thereby increasing their capacity for health and well-being. Thus, the research question explored in this

study is: How do adults with MDR- TB who undergo long- term hospitalisation at a hospital in the Western Cape experience occupational adaptation?

## **1.2 SIGNIFICANCE OF THE STUDY**

As there is a paucity of literature relating to occupational therapy within the TB context, understandings generated through this study will aide the development of appropriate occupational therapy intervention to facilitate occupational adaptation in TB patients. It is envisaged that the findings of the study will be utilized to inform occupational therapy intervention with TB patients who undergo long-term hospitalisation and in so doing, contribute to positive treatment outcomes in this context.



## **1.4 AIM AND OBJECTIVES OF THE STUDY**

The aim of the study was to explore how adults with MDR- TB who undergo long-term hospitalisation at a hospital in the Western Cape experience occupational adaptation.

The objectives of the study were:

- (i) To explore how the participants' perceive their occupational identity,
- (ii) To explore the meaning and purpose the participants' assign to their occupational engagement, and
- (iii) To explore how the participants perceive their occupational competence.

## 1.5 CONCLUSION

In this chapter this study was contextualized in terms of the background to the TB epidemic in South Africa and the rationale for the study. The significance of this study and the role it could play in contributing to improved treatment outcomes for MDR- TB patients in South Africa was highlighted. Finally, the aims and objectives for this study were described. In the following chapter a review of relevant literature pertaining to the key issues addressed in this study is presented.



## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

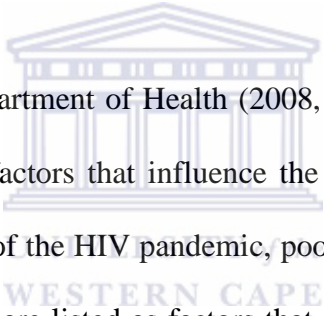
The literature reviewed in this chapter firstly contextualizes the TB epidemic in South Africa. Accordingly, literature related to factors that contribute to the progression of the disease and the management of the disease in South Africa is reviewed. The chapter secondly provides a synthesis of the relationship between occupation and health as well as the role that occupational therapy plays in reducing the effects of occupational risk factors associated with long-term hospitalisation. Literature pertaining to the process of occupational adaptation is also reviewed. Lastly, literature that addresses occupational therapy intervention specific to the facilitation of occupational adaptation is reviewed.

#### **2.2 THE BURDEN OF TB IN SOUTH AFRICA**

According to the WHO (2007) TB is the second leading cause of death that results from infectious diseases in the world today. Grimwood et.al. (2006) state that South Africa is one of 22 high burden TB countries in the world. Globally, the incidence of TB is particularly rife in developing countries. To this end South Africa holds the fourth highest estimated total of TB cases behind India, China and Indonesia despite these developing countries having much higher populations

(Department of Health, 2009). It is further reported that more than 24 000 South Africans were diagnosed with TB over the period of 2004 to 2008 (WHO, 2008).

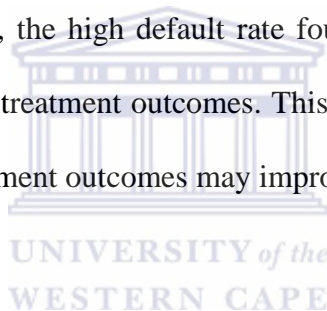
MDR TB is caused by bacteria that are resistant to isoniazid and rifampicin, the two most effective anti-TB drugs available (WHO, 2010). With regards to South Africa, the WHO (2008) estimates that a total of 14 000 MDR TB cases arise in the country annually. This is corroborated by the Department of Health (2008) which indicates that over the period of January 2004 to April 2007 there were over 16 000 MDR- TB cases across all of the provinces in South Africa, with the highest burden being 32% in Kwa- Zulu Natal and 23% in the Western Cape.



In South Africa, the Department of Health (2008, 2009) has paid much attention to the socio- economic factors that influence the development of TB. Poverty, urbanisation, the impact of the HIV pandemic, poor health infrastructure and poor programme management are listed as factors that contribute to the increasing TB burden while social issues are regarded as playing a key role in the progression of the TB epidemic (Department of Health, 2009). In elaborating on social issues that are related to the progression of TB, the department earlier declared that social issues such as poverty, stigmatisation of the disease, substance abuse, unemployment and limited access to health care facilities have a serious impact on the treatment adherence of patients and therefore the progression of the epidemic in South Africa (Department of Health, 2004). The department further states that refusal of medical treatment; requests for discharge from hospital whilst still infectious; discontinuance of treatment due to poor compliance; treatment failure

and adverse effects of the medication significantly impacts families and communities (Department of Health, 2008).

The Department of Health (2009) asserts that poor management of individual cases and patients' lack of insight into their pathology lead to poor treatment adherence thereby magnifying the TB epidemic. It argues that drug resistant TB largely results from human error and identifies poor patient adherence as one of the main contributing factors to MDR- TB. Treatment adherence is also linked with treatment outcomes. For instance, Medecins Sans Frontieres (MSF, 2009) states that although treatment outcomes are acceptable amongst those patients that complete their treatment, the high default rate found amongst those who do not are associated with poor treatment outcomes. This indicates that should treatment adherence improve, treatment outcomes may improve as well.



### **2.3 THE MANAGEMENT OF MDR TB IN SOUTH AFRICA**

The medical treatment of MDR-TB is a lengthy process. For instance, the South African National Tuberculosis Control Programme (Department of Health, 2004) indicates that the treatment of normal pulmonary TB, provided as an out patient service at the district clinics, takes six months to complete. In contrast to the management of normal pulmonary TB, MDR- TB patients are required to be on treatment for a period of at least 18- 24 months. This includes compulsory hospitalization for a period of at least 6 months or until at least two consecutive monthly sputum cultures are negative before they can be discharged (Department of Health, 2009).



On discharge, patients continue their treatment at a primary health care facility and are evaluated monthly by the MDR TB unit. The practical guidelines for the management of Drug Resistant Tuberculosis indicate that the monthly monitoring of MDR- TB should focus on regular drug susceptibility testing, counselling and support from a social worker or nursing professional so that should treatment be interrupted, the situation could be handled promptly and effectively (Department of Health, 2004).

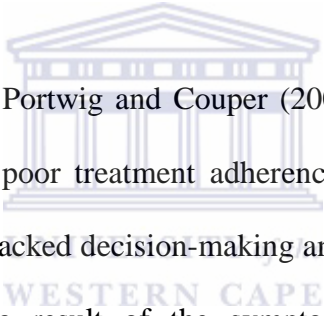
Strategies for example the Directly Observed Treatment Strategy (DOTS) and MSF's Decentralised model of Drug Resistant TB have been put in place to address issues such as poor treatment adherence. The National Guidelines for TB Management and MSF both emphasise that education and counselling of patients, adopting a caring, client-centred approach as well as family involvement, are pivotal in ensuring treatment adherence and successful treatment outcomes (Department of Health, 2009). The Department of Health (2008) emphasises that patients in a poor clinical condition, with a previous history of treatment interruption and those with complications such as haemoptysis or severe side effects, should not be considered for discharge or ambulatory (out- patient) care. Due to the rise in patient numbers and the unavailability of hospital beds the guidelines state that treatment can be commenced in the community after consultation with a specialist at an MDR TB unit with monthly follow ups at the MDR TB unit.

## **2.4 TREATMENT ADHERENCE IN THE TB CONTEXT**

The impact of treatment adherence on the progression of TB remains a major concern for The South African Department of Health. According to The Department of Health (2009) there are four sets of contributing factors to poor treatment adherence in TB patients. The first set of contributing factors is social and economic factors which include extreme poverty, poor support networks, unstable living circumstances, substance abuse and personal beliefs about TB and its treatment. The second set of contributing factors relates to health system factors which include poor health infrastructures, poorly trained and supervised personnel, low levels of accountability for health staff, poor relationships with clients and inadequate development of community based support for patients. The third set of contributing factors namely client related factors, are linked to stigmatisation of the disease, depression, disempowerment and poor knowledge about TB and the efficacy of treatment. The final set of factors is therapy related issues and include complex treatment regimens, large amount of pills that need to be consumed, adverse effects of medication and long treatment duration.

Matabesi and Booyesen (2004) as well as Portwig and Couper (2006) conducted two separate studies related to treatment adherence in the Free State Province and the town of Wellington, South Africa, respectively. Both studies investigated reasons for poor treatment adherence among TB patients. The key findings in both studies linked poor treatment adherence to low socio-economic status. In each study the researchers concluded that TB is a stigmatised disease and that TB patients experience a lack of support from health workers, family and friends. The

length of the treatment period also emerged as a contributory factor to the temptation to discontinue TB therapy. The quantitative findings in Matabesi and Booyesen's (2004) study further specified that stigmatisation, socio-economic circumstances of patients, and migrancy all play important roles in non-adherence, while the qualitative findings of the study identified a lack of knowledge about TB, non sustainability of educational campaigns, side-effects of drugs, hunger, lack of family support, the attitude of health care workers, stigma, and the long delay before diagnosis as factors that contribute to treatment adherence. The researchers recommended that various patient- and community-centred interventions be implemented to improve adherence.



The study conducted by Portwig and Couper (2006) highlighted a link between psychosocial issues and poor treatment adherence. The findings revealed that participants in the study lacked decision-making and coping skills and displayed a lack of motivation as a result of the symptoms or side effects that they experienced while on medication. Group pressure, poor self-esteem, distance from the clinic as well as problems with the continuity of care and a lack of family or community support also contributed to poor adherence. Portwig and Couper (2006) assert that patients should not carry the primary responsibility for their adherence but recommend that they be regarded as part of the team who take responsibility for it. They suggest that if TB treatment is to be optimised, patient cooperation and information need to be addressed as these are essential for treatment success. They further assert that existing services need to be made more accessible and acceptable and that health care service providers should make an

additional effort to educate the community about TB and the factors associated with the progression of the disease.

Another issue related to treatment adherence is that of long-term hospitalization. According to MSF (2009) current national policy on the management of TB in South Africa is aimed at centralised care in specialised regional treatment centres where patients diagnosed with MDR TB have to spend at least six months in mass wards. MSF (2009) however argues that there is little evidence to prove that long-term hospitalisation improves adherence or prevents transmission of the disease. They assert that as specialised hospitals are situated far from the homes of the patients, hospitalization leads to feelings of isolation and neglect amongst patients. This ultimately effects adherence negatively and result in a very high default rate with some patients simply refusing to remain in hospital. The Department of Health (2008) also asserts that specific legislative frameworks and public health ethics should be considered when drawing up treatment guidelines. Examples of these are the right of human dignity; the right of privacy; as well as the rights of freedom of movement, trade, occupation and social security. This set of patients' rights highlights individuals' right to health and well-being. In particular it draws attention to the effects of long-term hospitalisation on the health and well- being of TB patients.

## **2.5 DEFINITIONS OF HEALTH AND WELL- BEING**

WHO (1948) defines health as a state of complete physical, mental and social well-being and not merely the absence of disease. WHO (1986) further states that

individuals should be able to satisfy their needs and in so doing, change or cope with their environments in order to reach this state of well-being. Epp (1986, cited in Law, Steinwender & Leclair, 1998) agrees with the WHO definition of health by stating that definitions of health have evolved from an initial emphasis on disease and mortality to health being considered as a resource and part of everyday life. He cites the Ottawa Charter (WHO, 1986) definition of health which states that context plays an important role in one's health and well-being as people create a sense of health and well-being based on the settings of their everyday lives.

Epp (1986, cited in Law, Steinwender & Leclair, 1998) further states that a state of health is achieved by being able to care for oneself and others as well as being able to make decisions and take control over one's life circumstances provided that the society or environment one lives in allows for this to be attained. This implies that health and well-being is also attained through finding a balance between one's mental, physical, and social characteristics. Likewise, Orem (1985, cited in Law et.al, 1998) asserts that well-being is a term that is used to describe an individual's perception of their ability to integrate their physical, mental, emotional, spiritual and social characteristics.

## **2.6 HEALTH, WELL-BEING AND HUMAN NEEDS**

According to Max-Neef (1991), a Chilean economist, people can only experience health and well-being when their fundamental human needs are met. He asserts that not having one's needs met results in ill-health or pathology that may be

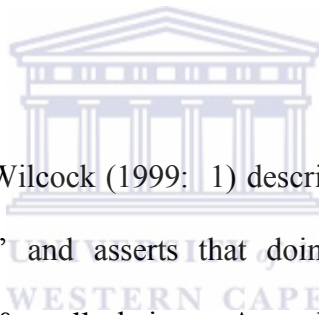
personal, political or economical in nature. Max-Neef (1991) argues that human needs are interrelated and interactive and that by understanding human beings in terms of deprivation and potential, one will realise that people's needs cannot be restricted to specific categories. In contrast to Maslow's (1943) theory which portrays human needs in a hierarchical shape of a pyramid with physiological needs at the bottom followed by safety and security needs, the need for love/belonging and finally the need for self-actualisation at the top of the pyramid, Max-Neef argues that there is no hierarchy of needs. He asserts that human needs occur simultaneously and that they are complementary to each other.

According to Max-Neef (1991) there are nine fundamental human needs that can be grouped into two categories i.e. axiological and existential. The axiological categories are subsistence, protection, affection, understanding, participation, idleness, creation, identity and freedom. The existential categories are being, having, doing and interacting. Max-Neef (1991) indicates that the existential categories represent freedom and personal choice and the axiological categories represent recognition and acceptance of specific values. He asserts that in order for development (and thus health/wellness) to occur, both existential and axiological needs must be satisfied.

## **2.7 HEALTH, WELL-BEING AND OCCUPATION**

Several authors suggest that there is a relationship between health, well-being and occupation as occupation as part of a balanced lifestyle, is a natural biological mechanism for health (Law et al., 1998; Wilcock, 1999; Rudman, 2002; Pentland

& McColl, 2008; Hammel, 2009a). Wilcock (1993) emphasises that humans are occupational beings who need to use time in a purposeful way. She argues that this is an innate need which relates to health and survival in that it enables individuals to utilise their capabilities and potential thus allowing them to thrive. Wilcock asserts that people have a need to utilise their capabilities through engagement in occupations and that they should be encouraged to pursue this need in order to not only provide sustenance, survival and security, but to improve their overall health. Rudman (2002) concurs with Wilcock by stating that occupational engagement can fulfil basic human needs by providing people with a sense of purpose, a means to organise their time and a means to develop and express their identity.



In defining occupation, Wilcock (1999: 1) describes it as a synthesis of ‘doing’, ‘being’, and ‘becoming’ and asserts that doing or not doing are powerful determinants of health & well-being. According to Wilcock, ‘doing’ is so important in people’s lives that it is impossible to envisage the world without it. She states that the dynamic balance between ‘doing’, ‘being’, and ‘becoming’ encompasses what people do and who they are as human beings. ‘Doing’ provides a mechanism for development, ‘being’ refers to one’s nature of being true to one’s self in all that one does while ‘becoming’ symbolises a sense of the future and holds the notion of self-actualisation. Hence, through engaging in occupation, individuals are in a constant state of transformation.

It is Rudman’s (2002) view that occupations influence people’s sense of personal identity i.e. the perception people have of themselves as well as their social

identity in that occupations allow people to express who they are to others. Rudman (2002) asserts that occupational engagement leads to opportunities for growth and that a limitation in occupational engagement limits the way in which people perceive themselves and manage their social identity. Rudman (2002) further states that the sense of control that people exert over their occupation is an important determinant of the contribution that it makes to their lives.

Law et. al. (1998) reviewed 23 studies with the aim of establishing a link between health, well- being and occupation. From the review the authors concluded that an individual's stress levels and perceived control within a situation impact on his/her health. For instance, higher stress levels lead to decreased perceived control impacting health negatively. Law et. al. also concluded that an increase in free time, with fewer opportunities to 'do' is associated with decreased satisfaction and subsequent decreased health. In addition, when individuals experience a challenge and when they learn something, they experience greater satisfaction. Law et. al. further concluded that it is not the type of activity people engage in but rather its characteristics like choice, control, and intrinsic motivation that lead to increased satisfaction and thus increased health.

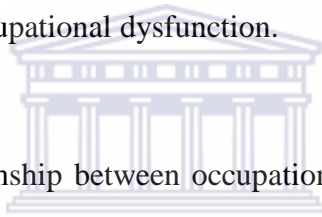
In support of Law et. al., Wilcock (2006) states that people's doing, being and becoming can lead to either or both positive and negative health outcomes. Ill-health can therefore be seen as an outcome of unsatisfactory doing, being, and becoming, which according to Wilcock (2006), may be influenced by an individual's exposure to occupational risk factors. She therefore asserts that it is



imperative that occupations provide people with sufficient physical, mental and social meaning, thereby allowing them to meet their unique becoming needs.

## **2.8 OCCUPATION AS MEANING AND PURPOSE**

According to Hammel (2009b) occupations can hold negative meaning when the person that engages in them experience boredom, humiliation and frustration. Kielhofner (2002) considers individuals whose occupations lack meaning and purpose to be in a state of occupational dysfunction. He regards people's inability to choose, organise or perform particular occupations and a lack of direction in life as dimensions of occupational dysfunction.



In addressing the relationship between occupation and the meaning and purpose that occupational engagement holds for an individual Nelson (1988) developed a theory that defines occupation as the relationship between occupational form and occupational performance. Occupational form refers to the physical, temporal and social context of the individual whereas occupational performance is the doing or active behaviour. He explains that meaning is derived from an individual's interpretation of the occupational form i.e. meaning arises from the personal and/or cognitive sense that something makes to an individual. Nelson further states that all occupations include a sense of purposefulness. Purpose is described as the goal orientation of the individual and the link between an individual's developmental structure i.e. abilities or attitudes, and other qualities that individuals have which enable a response to the occupational form. Nelson explains that the individual purposefully organises these structures to achieve

goals that are derived through the meaning established from the occupational form (context) thus occupational performance becomes purposeful.

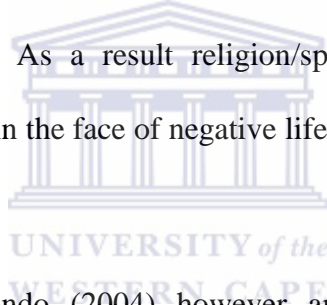
According to Hammel (2009a) occupations should not purely be defined by doing but that it should be defined by how people experience it. Hammel (2004) states that meaning, purpose, choice, control and a positive sense of self worth affect the way in which people experience occupation. She suggests that meaningful occupations should contribute to a person's sense of belonging and feeling valued in everyday life as well as provide hope for the future. Additionally, she asserts that spirituality influences the meaning and purpose that people attach to their occupations and that it plays a role in how people experience their occupations. According to Hammel (2004) Canadian occupational therapists have made spirituality the core of their intervention as it has been their experience that clients who undergo disruptions in their lives relate meaning, purpose and values to their spirituality.

## **2.9 SPIRITUALITY AND HEALTH**

Spirituality and religion have a strong link and are often seen as dependent on each other. For this reason George, Larsons, Koeing and McCullough (2000) state that defining spirituality on its own is very complex. They argue that both religion and spirituality are based on sacred beliefs (referring to a divine being or higher power) and that these beliefs impact people's behaviour. They state that the only difference between religion and spirituality is the fact that while religion

is linked to formal religions institutions, spirituality is not linked to any formal institution.

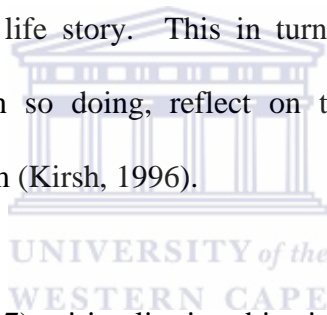
Some authors for example Dein (2006) uses the words spirituality and religion interchangeably, while others such as Weskamp and Ramugondo (2004) argue that religion and spirituality should be viewed separately. Dein (2006) states that religion/spirituality may provide people with a cognitive framework that enables a healthier evaluation of the stressors that occur in their lives. She furthermore asserts that specific types of spiritual/religious coping are associated with positive psychological outcomes after negative life events as well as a higher self esteem and better adjustment. As a result religion/spirituality may provide greater psychological resilience in the face of negative life events.



Weskamp and Ramugondo (2004) however argue that it is imperative to differentiate between spirituality and religious beliefs in that religion is associated with constructed doctrines, dogma and a specific manner of worship. They assert that it is possible to be spiritual without being religious in that spirituality can be experienced informally and may be intangible as it occurs within an individual. Weskamp and Ramugondo (2004) state that spirituality provides people with hope and are often attributed to positive experiences that are essential for a meaningful life. They therefore question whether it is possible to have hope and achieve meaning and purpose in spirituality while experiencing occupational risks. Consequently, Weskamp and Ramugondo (2004) argue that spirituality should be an integral part of interventions that address occupational risk factors. Feeney and

Toth- Cohen (2008) concur with Weskamp and Ramugundo in that they assert that failure to respond to clients' spiritual needs will result in ineffective intervention, as spirituality is central to many clients' lives and is often what is most meaningful to them.

In addressing interventions that include spirituality, Kirsh (1996) suggests the use of narratives as part of occupational therapy intervention as it provides clients a means of reflecting on personal experiences and/or difficulties associated with their condition. She asserts that in encouraging clients to construct their story it is acknowledged that the meaning and purpose in their experience in their lives is strongly linked to their life story. This in turn allows them to develop their personal identity and in so doing, reflect on the meaning and purpose that spirituality holds for them (Kirsh, 1996).



According to Unruh (1997) spirituality is subjective in that it is personal, intimate and private. She states that each person, depending on the person's awareness and acceptance of spirituality, will incorporate spirituality into their lives in a way that he or she is most comfortable with. She however questions whether spirituality has the ability to hamper some occupations while being able to facilitate others. For example, she states that the occupation of gardening may allow a person to express or renew their spirituality, while the occupation of substance abuse will have a negative impact on the person engaging in the occupation.

Wilding (2007) also draws attention to the relationship between spirituality and occupation. According to her spirituality is a form of being that provides the

meaning that underpins doing. In a study she conducted to explore the relationship between spirituality and occupation the participants expressed that their spirituality made it easier for them to engage in everyday occupations as they felt connected to other people and thus experienced more meaning (Wilding 2007). She concludes that spirituality can provide hope, provide someone with a reason to live, support a person in his or her daily life and provide meaning to everyday occupations. Wilding (2007) also asserts that spirituality helps people cope with their illness as it provides emotional support and is therefore directly related to people's health.

## **2.10 OCCUPATIONAL RISK FACTORS AND ILL-HEALTH**

According to Wilcock (1998), occupational risk factors are factors that could lead to health disorders such as boredom, burnout, decreased fitness, mental illness, physical illness and ultimate disability or death. She states that occupational risk factors occur as a result of doing too much or too little i.e. occupational imbalance; finding little meaning and purpose in doing i.e. occupational alienation, and lacking opportunities to strive towards becoming i.e. occupational deprivation.

When Wilcock (1998) defines occupational imbalance she acknowledges that people's experiences of work, rest and play are subjective, therefore she refers to occupational imbalance as a state that occurs when an individual's occupational engagement fails to meet their unique social, mental or rest needs. She states that balancing one's physical, social and mental capacities with rest is important if one

wants to achieve health and well-being. Similarly, in terms of occupation, individuals should be able to maintain a balance between work, rest and play. Wilcock (1998) Occupational imbalance will therefore differ from person to person in relation to their capacities, interests and responsibilities and could result in either burnout or boredom.

Occupational alienation is associated with feelings of frustration, isolation and separation from a particular occupation when individuals' needs are not met by engagement in a particular occupation Wilcock (1998). It is for this reason that Hagedorn (2001) asserts that people who experience occupational alienation feel that their occupations are meaningless and unfulfilling.

Wilcock (1998) defines occupational deprivation as people's inability to engage in occupations due to some external restriction. Examples of such external restrictions are technology, division of labour, lack of employment opportunities, poverty, affluence, illiteracy, prejudice, cultural values, local regulations, limitations imposed by social systems and ill-health or disability (Wilcock, 1998). Similarly, Whiteford (2005) defines occupational deprivation as a person's state of long lasting deterrence from engaging in particular occupations due to factors that are outside of the control of the individual. This was illustrated in a study that focussed on the lived experiences of refugees from Kosovo who resettled in Australia and revealed the effect of occupational deprivation on people's health and wellness (Whiteford, 2005). The key findings of the study indicated that the refugees not only experienced occupational deprivation but that they also experienced occupational alienation as being out of their natural context,

they could not engage in their natural occupations resulting in them experiencing a lack of meaning. In addition, the refugees felt that they were discriminated against due to their origin. The findings also highlighted the important role that cultural expression and appropriate activities could play in the alleviation of occupational risk factors.

## **2.11 LONG -TERM HOSPITALISATION, INSTITUTIONALISATION AND OCCUPATIONAL RISK FACTORS**

There are several authors who associate occupational risk factors with institutionalisation (Snowdown, Molden & Dudley 2001, Duncan 2004, Barros, Ghirardi, & Lopes 2005, Bynon, Wilding & Eyres, 2007, Farnworth and Muñoz , 2009). For instance, Bynon et. al., (2007) assert that despite the fact that hospitals are usually associated with restoration of health, hospitalisation can also have a negative impact on health and well- being. Similarly, Farnworth and Muñoz (2009) state that people experience both occupational deprivation and occupational imbalance when they undergo long-term hospitalization. They argue that people who are institutionalised are not able to freely choose the occupations in which they engage and are therefore limited when it comes to occupational engagement. They assert that due to the fact that routines are highly structured and monotonous, and allows for little or no choice and opportunity for purposeful occupational engagement, occupation becomes meaningless to the individual and impacts negatively on his/her health and well- being. Farnworth and Muñoz (2009) further assert that institutionalisation leads to people being disconnected from society and limits opportunities to develop habits and routines which further

impacts negatively on health and well-being. Institutionalization thus impacts a person's occupational identity which according to Hagedorn (2001) is the way in which persons perceive themselves as occupational beings.

Long-term hospitalisation also has an effect on the behaviour of patients with mental health problems. With regards to this, Snowdown et al (2001) state that institutionalisation leads to patients becoming apathetic and passive as they lose interest in anything that is happening outside the institution. They assert that behavioural problems such as aggression and self-destruction are rife in patients who undergo long-term hospitalisation and stress that such behavioural issues are usually related to the nature of the institution. This nature may encompass factors such as enforced idleness, negative staff attitudes, lack of friends, lack of possessions, loss of contact with the outside world and the general atmosphere in the hospital wards which all contribute to the institutionalisation (Barton, 1959 cited in Snowdown et.al 2001). Snowdown et al (2001) further state that as patients who are institutionalised become dependant on the institution it hampers their self-esteem and decision-making abilities thus reducing the control they have over their environment.

An association of occupational risk factors with institutionalisation has also been made in the context of the incarceration of prisoners. Whiteford (1997) as well as Molineux & Whiteford (1999) conducted two separate qualitative studies on occupational deprivation in the prison setting in New Zealand and London respectively. The findings in each of the studies indicated that deprivation was evident in each prison setting due to the lack of occupational choices experienced by the prisoners. This resulted in them being bored, de-motivated and



experiencing deterioration in their physical and cognitive functioning. In addition, Whiteford (1997) found that the rigid rules within the prison, specifically around the no tools policy, resulted in the prisoners being unable to initiate and engage in occupations that they found to be meaningful to them. Whiteford made recommendations regarding their daily and weekly programmes and suggested the prisoners be exposed to different facets of their environment. Moreover, she recommended that the use of tools be reintroduced in the prison thereby increasing their exposure to a wider variety of occupations over an extended period. She further suggested that this be introduced as part of an occupation based occupational therapy programme delivered independently of the medical programme. Likewise Moulineux and Whiteford (1999), in their study, recommended that occupational therapy interventions in the form of occupational enrichment programmes be implemented to address the occupational needs of the prisoners, thereby addressing institutionalisation, occupational risk and dysfunction.

Haney (2002) also addresses the institutionalisation of prisoners but elaborates on the difficulty they have in adapting to life after prison. He states that being able to survive prison and successfully reintegrate into the community requires a process of adaptation. He argues that when in prison, people become dependent on the institutional structure to such an extent that they forget how to use their initiative and how to be independent as they are denied control on a daily basis. As a result, when the structures of the institution are removed they no longer know how to do things on their own. Haney (2002) also argues that the effects of institutionalisation often only surface once the person has returned home. For

example, parents who return home after being institutionalised are often still dependant on the structures of the institution and still have that “over- control” of their emotions which result in social isolation. They also struggle to make their own decisions and therefore struggle to adapt and build relationships with their children and organise their children’s lives as they have an internal disorganisation.

In order to combat institutionalization in the case of prisoners, Haney (2002) recommends that programmes in prison should allow prison life to replicate normal life as much as possible and that prisoners should be given the opportunity to exercise some autonomy. He further suggests that there should be a consistent effort made to encourage visitation of families thereby diminishing the division between prison and the outside world. In addition, strategies should be put into place to develop prisoners’ insight into the changes brought on by prison life and to provide them with tools to assist their adaptation to the outside world. Moreover Haney (2002) states that there should be support mechanisms in place within communities to ease the transition from prison to home for example, providing quality services and support in the community from professionals as well as strengthening family systems through family counselling sessions.

## **2.12 OCCUPATIONAL ADAPTATION**

According to Schkade and Schultz (1992), all individuals have an inherent desire to engage in meaningful occupations with the aim of achieving a sense of mastery and competence in their occupations. This requires occupational adaptation,

which is a process through which the person and the environment interact when the person is faced with a challenge that calls for an occupational response. Schkade and Schultz (1992) developed the Occupational Adaptation Model as an integrative frame of reference aimed at guiding and organising the intervention process that is necessary to successfully facilitate occupational adaptation within individuals. The Occupational Adaptation Model (Schkade and Schultz, 1992) is comprised of four main constructs namely occupation, adaptive capacity, relative mastery, and the occupational adaptation process.

The first construct namely occupation, consists of three properties. The first property is the active engagement of the individual in an activity, the second property is that the activity must be meaningful to the individual and the third property is that the process of the activity must result in an end product. The second construct namely adaptive capacity is a person's awareness of the need for change, modification or adaptation in order to achieve occupational competence. It is demonstrated when an individual has difficulty in meeting the challenges of an occupation and the person modifies or adjusts his/her behaviours in order to achieve competence. The third construct namely relative mastery is based on the individual's ability to respond to their occupational demands through the use of time, energy and the availability of resources. Other factors that determine mastery include the effectiveness of the individual's response in relation to the successful achievement of their goal, as well as the level of satisfaction experienced by them in relation to their social identity. The fourth construct namely the occupational adaptation process, is a complex series of steps that

occur when an individual is faced with a specific occupational demand within their environment and role capacity.

Schkade and Schultz (1992) assert that the occupational adaptation process depicts how well a person can respond and adapt competently during occupational engagement. The adaptation process can however be disrupted by impairment, disability or environmental constraints. The three main components influencing the occupational adaptation process are the person, the occupational environment and the interaction between the person and the environment. According to Schkade and Schultz (1992) these components are regarded as equal in their influence of the occupational adaptation process. Below is an adapted diagram of the occupational adaptation process (Schkade and Schultz, 1992).

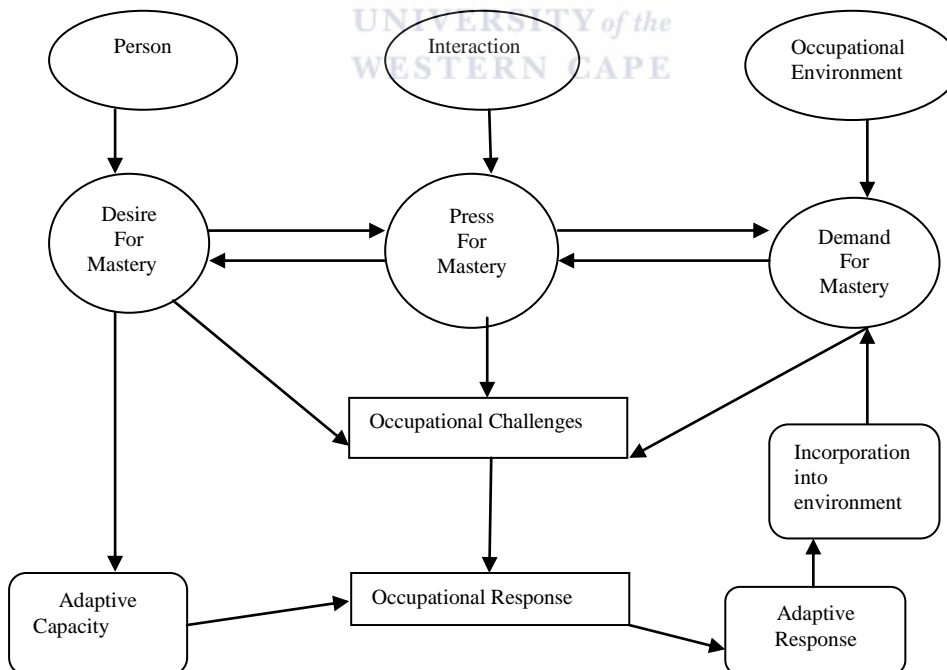



Figure 1: The occupational adaptation process (adapted, Schkade and Schultz, 1992)

According to Kielhofner (2007) occupational adaptation encompasses two components namely occupational identity and occupational competence. Occupational identity refers to a composite definition of the self, which includes one's roles, values, self- concept and personal goals. Occupational competence refers to the degree to which one sustains a pattern of occupations that reflects one's occupational identity. Kielhofner (2007) explains that while identity is linked to the subjective meaning of one's occupational life, competence is linked to putting that identity into ongoing action.

The Model of Human Occupation (Kielhofner, 1995) sheds more light on how occupational adaptation may be facilitated. The model is aimed at guiding an understanding of the relationship between an individual, the environment and the occupation. According to Kielhofner (1995), when an individual encounters positive experiences, which support the desire to explore, master and fulfil environmental demands. This allows the person's choices, routines and skills to promote positive behaviours, which lead to increased organisation. On the contrary, a maladaptive cycle occurs when a person experiences repeated disorganisation, poor performance and anticipation of future failure. Hence, the model implies that poor choices, poorly organised routines and deficient skills lead to increased disorganisation and a state of occupational dysfunction. This process of adapting to one's environmental needs what is known as occupational adaptation.

Klinger (2005) as well as Parsons and Stanley (2008) conducted two separate studies on occupational adaptation from the perspective of people who suffered

traumatic brain injury. The findings of Klinger's study indicated that the participants in the study had difficulty adapting to their new identity after the injury and that developing a new occupational identity was fundamental to an improvement in their occupational adaptation. Parsons and Stanley found that meaningful occupational engagement as well as acceptance of who they had become as occupational beings as a result of the brain injury was essential in the adaptation process of their participants. The findings of Parsons and Stanley's study further highlighted the importance of environmental and social support in maintaining a positive attitude towards the participants' rehabilitation process and ultimately in the adaptation process.



**2.13 OCCUPATIONAL THERAPY INTERVENTION STRATEGIES TO ADDRESS OCCUPATIONAL RISK FACTORS AND IMPROVE OCCUPATIONAL ADAPTATION**

In addressing occupational risk factors, Hammel (2009a) argues that occupational therapy intervention should allow everyone the opportunity to engage in occupations that have a positive impact on their health, while Wilcock and Townsend (2004) propose that intervention should also facilitate occupational justice in acknowledgement that people are occupational beings as well as social beings. According to Wilcock and Townsend (2004) an individual experiences occupational injustice when occupational risk factors such as occupational alienation, occupational deprivation and occupational imbalance occur. They state that autonomous engagement in occupations as well as enabling an individual's choice and control over occupational engagement comprise the

beliefs and principles that guide occupational justice. Furthermore, Wilcock and Townsend (2004) propose four occupational rights that aim at ensuring occupational justice. The four occupational rights are the right to experience occupation as meaningful and enriching, the right to develop through participation in occupations for health and social inclusion, the right to exercise autonomy through having a choice in occupation and the right to have the privilege of engaging in diverse occupations.

Kielhofner (2002) describes the role of an occupational therapist in addressing the needs of clients who present with occupational dysfunction as involving an understanding how mental, physical and environmental components contribute to the individual's occupational needs and/or dysfunction. He states that the goal of intervention should be to facilitate change through providing opportunity for the person to engage in specific occupations. Hammel (2009b) however argues that one should acknowledge how western cultures guide occupational therapy intervention and the impact it has on the efficacy of the implementation of such interventions in other cultures. She argues that although occupational therapy theories are largely developed in western cultures the majority of occupational therapists do not work with people from these settings. She asserts that where western cultures promote individualism and independence, other cultures focus on interdependence and connectedness which contributes positively to well-being. She therefore asserts that occupational therapy should not only focus on occupations purely in relation purely to self-care, work and leisure, but that they should also include prayer, caring for others, making love and supporting others as meaningful occupation.

With regards to intervention strategies to address occupational risk factors, several authors recommend occupational enrichment programmes as a means to address occupational deprivation and occupational imbalance (Moulineux & Whiteford 1999, Duncan, 2004, Farnworth and Muñoz, 2009). These authors state that occupational enrichment programmes aim to provide people with opportunities for autonomous choice, to advocate for independent structuring of daily routines and to provide opportunities for active participation in programmes which supports personal and skills development needed for successful integration into their families and communities. Duncan (2004) suggests that occupational enrichment allows individuals to access personally satisfying activities by addressing personal and environmental issues that could act as barriers against participation in meaningful occupations. She states that occupational enrichment recognises occupational risk factors and addresses the effect these risk factors have on the individual's occupational needs. Similarly, Moulineux and Whiteford(1999) define occupational enrichment as the deliberate manipulation of an individual's environment to support and facilitate meaningful occupations by addressing the needs of people who experience occupational risk.

The use of psychosocial rehabilitation principles are recommended when occupational risk factors are addressed and occupational enrichment programmes implemented (Duncan, 2004; Farnworth & Muñoz, 2009). The Southern Development Group (2003, cited in Duncan, 2004: 213) states that psychosocial rehabilitation focuses on “individualized, client centred care, which instils hope, and focuses on the strengths and abilities of the client while building a partnership



within a secure environment”. Farnworth and Muñoz (2009) suggest that a psychosocial rehabilitation programme should include topics such as adult literacy, vocational skills training, religious groups and groups focusing on community reintegration and support groups. They further state that intervention should aim at improving or maintaining daily living skills, as well as developing and redefining roles that will support successful community integration.

In terms of institutionalization, Barros et. al. (2005) and Duncan (2004) agree that occupational therapists have a role to play as social agents in reducing the effects of institutionalisation by allowing people to engage in activities which encourage socialisation and interrelationships. Barros et. al. (2005) describes deinstitutionalisation as a process of restructuring social and institutional processes thereby allowing people or societies to take control of their own problems through exploring alternate options. They suggest that deinstitutionalisation allows for the deconstruction of the culture associated with being institutionalised. Duncan (2004) supports this view and asserts that all people have rights and that their needs should be taken into account. Likewise, Bynon et. al. (2007) suggest that deinstitutionalization is optimised when patients are involved in individual therapy as well as groups, if time is spent identifying which occupations are most meaningful to the patient, if clear goals are set, if time is spent educating patients and families about the impact of occupational disruption and if patients are able to provide feedback about their experiences within the programme.

The Clubhouse Model of Psychosocial Rehabilitation is one example of a dynamic, all-inclusive intervention programme that was developed as a means of deinstitutionalisation for people who underwent long-term hospitalisation for mental illness (Fountain House, 1999; Norman, 2006; Cognilio, Hancock & Ellis, 2010). The International Center for Clubhouse Development (ICCD, 2011) define a clubhouse as a supportive community that allows its members to reconnect with friendships, family, work, employment and education where the focus is on a work ordered day as well as evening, weekend and holiday programmes. According to Fountain House (1999) the Clubhouse Model focuses on the strengths of its members and not on their illness and all participation is on a voluntary basis. The core principles of this model is that programme members are provided with a supportive environment where they are accepted and there is commitment to helping them meet their full potential; they have a place where they can belong as adults who have something to contribute as opposed to adopting the role of a patient; they are encouraged to work at the clubhouse or to explore employment opportunities in the community and they are allowed to choose the activities they engage in based on their interests and skills. Cognilio et.al. (2010) asserts that the Clubhouse Model provides peer support to its members and encourages a sense of social inclusion, belonging, interdependence and a shared sense of accomplishment through engaging in activities together.

## 2.14 CONCLUSION

From the above literature review, it is evident that the TB epidemic is a growing concern in South Africa especially with the emergence of MDR- TB, while policies and guidelines have been put into place to address the management of TB, the focus is still on the medical aspects of the disease and very little emphasis is put on the psychosocial components related to the disease. Adherence has emerged as a major contributing factor in the progression of the disease with socio-economic factors playing a major role in treatment adherence of TB patients. MDR- TB patients are hospitalised for long periods of time to ensure adherence as well as to protect communities from becoming infected with MDR-TB. The review highlighted the relationship between health and human needs in terms of having basic human needs and health and occupation in terms of being able to engage in occupations that are meaningful. The review further revealed that spirituality impacts the meaning that people attach to their occupational engagement and thus impacts people's health and well-being. The literature review also brought to light the link between long-term hospitalisation, institutionalisation and occupational risk factors. Finally, attention was drawn to the role that occupational therapy could play in addressing occupational risk factors that result from institutionalisation by facilitating a process of occupational adaptation in individuals. Specific occupational therapy intervention strategies through which this can be achieved were highlighted. In the following chapter the methodology that was applied in this study is presented.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 INTRODUCTION**

The aim of this study was to explore how adults with MDR- TB who undergo long-term hospitalisation at a hospital in the Western Cape experience occupational adaptation. The objectives of the study were to explore how the participants' perceive their occupational identity, to explore the meaning and purpose the participants' assign to their occupational engagement and to explore how the participants perceive their occupational competence. In this chapter the research setting, research paradigm, research approach, research design and participant selection is described. In addition, I present the data collection methods, the data analysis process as well as how rigour and trustworthiness was maintained in this study. Finally, I describe the ethical considerations that were implemented in this study.

#### **3.2 RESEARCH SETTING**

The setting for this study is a TB hospital in the Western Cape province of South Africa. The bed capacity at the hospital is 360. There are six adult wards at the hospital of which two wards accommodate MDR- TB patients. Each adult MDR TB ward accommodates approximately 45 patients. Three of the adult wards (Male MDR ward, Female XDR ward and male XDR ward) have fences around

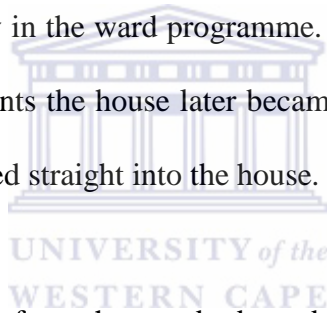
them to serve as an isolation unit with the purpose of preventing cross infection of patients. The hospital rules stipulate that the patients may only leave these wards with the permission of the nursing sister in charge. These wards each have a recreation room within the perimeter of the fence. The male wards have a pool table a TV and a lounge suite and the female ward has a cooking area instead of the pool table. The recreation rooms are managed by the nursing sister in charge of the ward and are kept locked after 17h00 every day.

Each hospital ward has 6 bedrooms of which the two largest accommodate 10 to 12 patients, the two smaller rooms accommodate 6 patients and the two smallest rooms accommodate two patients. As each patient is only allocated one locker in which to keep their belongings they are advised to keep only a few personal items in the hospital. There is one communal bathroom that is used by all the patients (45 in total) that reside in the ward. The décor in the wards is very clinical and not personalised according to patients preferences, although some patients have their own linen on their beds. The wall space above some of the patients' beds is decorated with family pictures and/or certificates of attendance for participation in the ward programme that are issued to them by the occupational therapy department.

The hospital wards are under 24 hour nursing supervision. The cleaning staff in each ward is responsible for maintaining the general cleanliness of the ward during the day. Meals for each ward are prepared in the hospital kitchen and are delivered to the wards at meal times (Breakfast: 8am- 9am, Tea: 10h30, Lunch: 12pm- 1pm, Supper: 4pm-5pm, Tea, 6pm). The patients also receive tea and

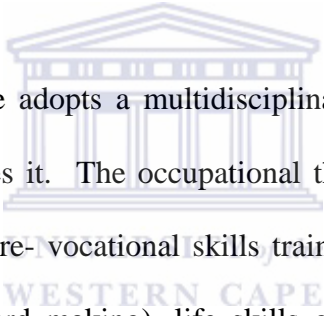
bread as snacks twice a day. They do not have access to the kitchen and are not allowed to prepare meals in the ward. There are strict hospital rules (see Appendix 1) that the patients must adhere to and patients are informed of these rules on admission to the hospital.

Two staff houses on the hospital premises have been converted into patient houses which serve as an extension of the female MDR- TB ward. These houses accommodate 22 patients altogether; one house accommodates 10 patients and the other accommodates 12. The patient houses were initially established as an incentive programme for adherent patients who were no longer infectious and who participated actively in the ward programme. Due to the press for additional beds for MDR- TB patients the house later became a mere extension of the ward and patients were admitted straight into the house.



The patient houses differ from the standard wards in that there is a maximum of three patients sharing a room, so they have more privacy. Each patient in the house has her own wardrobe. In contrast to the wards where they have 24 hour nursing supervision and cleaning staff, the patients in the house have to do their own chores and are not under the supervision of a nurse 24 hours a day, however, their meals are still prepared in the hospital kitchen. There is a kitchen in each house and patients can prepare their own snacks after hours if they choose to. This is a privilege the patients in the wards do not have. There is also a washing machine in each house so that patients can do their own laundry. The same general hospital rules apply to patients residing in the houses.

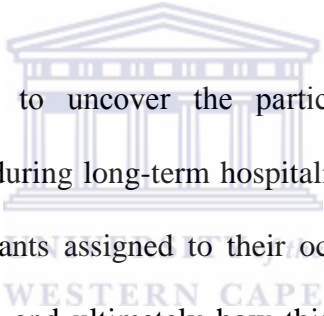
A multidisciplinary programme (see Appendix 2) was designed for all the long-term MDR TB patients including the patients residing in the patient houses as well as the XDR TB patients. The patients in each ward are divided into 4 groups and are allocated time slots for specific sessions. The male and female wards are seen separately and on alternate days of the programme. The purpose of the programme is to provide the patients with more structure in their daily routines as well as to provide them with opportunities for occupational engagement. The structure also allows for the staff to ensure that they allocate specific times to implement intervention for each ward. The programme runs from Monday to Friday and there are no activities taking place over weekends.



Although the programme adopts a multidisciplinary approach, the occupational therapy department drives it. The occupational therapy component of the ward programme consists of pre-vocational skills training (beading, sewing, contract work, fabric painting, card making), life skills groups, behaviour modification groups, stress management and relaxation therapy, cooking and baking sessions as well as recreational and social activities (pool, foosball, library, movies and Valentine's Day, Spring Day, Mother's Day, Sports day events). Due to the low staff patient ratio i.e. one occupational therapist/ physiotherapist/ psychologist allocated to six adult wards, the programme does not run effectively in all the wards. Due to staff shortages within the occupational therapy department, the occupational therapy programme was facilitated in one of the adult wards and the two houses only at the time of data collection.

### 3.3 RESEARCH PARADIGM

The interpretivist research paradigm was utilised in this study. According to Babbie & Mouton (2001), interpretivism acknowledges that people are constantly engaged in the process of interpreting their lives and assigning meaning to, justifying and rationalising their actions. They state that the fact that people constantly develop and alter their interpretation of their lives is grounds for social science research. Babbie and Mouton (2001) assert that the interpretivist research paradigm allows participants to provide their subjective perspectives of their lives and interpretations thereof, in rich detail.



In this study I aimed to uncover the participants' perspectives of their occupational adaptation during long-term hospitalisation. I explored the meaning and purpose the participants assigned to their occupational engagement during long-term hospitalization and ultimately how this influenced their occupational adaptation while hospitalized. The interpretivist paradigm facilitated my understanding of these phenomena as it allowed me to explore the meanings that participants assign to them (Rowlands, 2005).

Contrary to the positivist framework, the interpretivist framework does not pre-define dependant and independent variables and does not set out a hypothesis. Instead it aims to produce an understanding of the social context of the phenomenon as well as how the phenomenon influences or is influenced by the social context (Rowlands, 2005). The phenomenon that was under investigation in this study is long-term hospitalisation and occupational adaptation. The social



context is the hospital where the participants underwent long-term hospitalisation. As this study aimed to explore how adults with MDR TB experienced occupational adaptation while they underwent long-term hospitalisation, the utilization of the interpretivist paradigm was appropriate for the study as it allowed me to gain a deeper understanding of the participants own perspectives on their occupational adaptation.

### **3.4 RESEARCH APPROACH**

The perceptions and experiences of the participants formed the essence of this study and therefore a qualitative research approach was utilised. According to Walliman (2006) qualitative research is based on the experiences, descriptions, opinions, feelings and interpretations of research participants. Babbie and Mouton (2001) state that all qualitative designs share similarities in that the focus is on detailed engagement with the objects of the study, that a small number of research participants are selected, that there is an openness to multiple sources of data and that it allows the researcher to make changes or adapt the study where applicable. They assert that understanding behaviours, actions and processes within the context of the participants is important in qualitative research. In addition, Babbie and Mouton (2001) as well as Terre Blanche and Kelly (1999) suggest that the qualitative research approach allows the researcher to engage with the participants in their natural setting, thereby allowing the researcher to gather data which is rich and in depth. In this study, the hospital was the participants' natural setting and as I wanted to determine how they experienced occupational adaptation while

undergoing long-term hospitalisation, utilizing the qualitative research approach was suitable for this study.

According to Ospina (2004), qualitative research allows the researcher to understand social phenomenon from the perspective of the people involved, rather than explaining it from the outside. Engaging directly with the people involved in the phenomenon being studied and getting a first hand account of their perspectives and experiences accomplish this (Ospina, 2004). Accordingly I engaged with the research participants directly in order to gain insight into their first hand experiences of long- term hospitalization. In contrast to quantitative research, which aims for establishing empirical values relating to the researcher's understanding, qualitative studies aim for an in depth understanding of the data (Henning, Van Rensburg & Smit, 2004). Furthermore, qualitative research seeks to evoke responses that are meaningful and culturally relevant to the participant (Mack, Woodson, Macqueen, Guest & Namey, 2005).

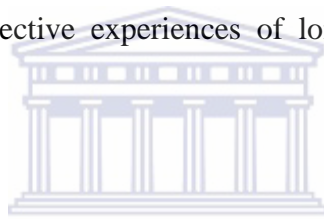
In this study I aimed to gain an in depth understanding of how patients who undergo long- term hospitalisation experience and perceive their occupational adaptation. Qualitative research was therefore suited for this study as the focus of the study was on the lived experiences and perceptions of patients who are hospitalised for a long period of time. Qualitative research methods also provided a means through which I was able to analyse the findings and describe it in rich detail from the perspectives of the participants. Qualitative research was further deemed appropriate for answering the research question of this study i.e. how do patients who undergo long term hospitalisation perceive their occupational

adaptation, as it allowed me to elicit an in depth understanding of the participants' perceptions, understanding and experiences of their occupational adaptation while being hospitalised.

### **3.5 RESEARCH DESIGN**

This research study followed a phenomenological research design. Qualitative research designs include ethnography, life histories and case studies (Babbie and Mouton, 2001). While ethnographic studies focus on larger entities or communities, case studies focus on a more specific entity such as families, institutions or communities and life histories focus on one or more individuals (Babbie and Mouton, 2001). Finlay (2009) asserts that phenomenological researchers explore fresh, complex phenomenon in rich detail where the focus is on the lived experiences of the people directly linked to a phenomenon. Finlay further asserts that phenomenological research provides concrete, first hand descriptions of lived experiences of the research participants. Also, Eichelberger (1989) states that as each person has a unique set of experiences, phenomenological research allows the researcher to find commonalities as well as contradictions and inconsistencies in the participants' responses. In this study the phenomena under investigation are the participants' experiences of long- term hospitalisation and their experiences of occupational adaptation while being hospitalised. In relation to this, a phenomenological design allowed me to explore each participant's unique experience of their occupational engagement during long- term hospitalization and the specific meaning and purpose that it held for them.

Lester (1999) highlights a link between phenomenology and qualitative research. He states that phenomenology focuses on studying a phenomenon from the perspective of the participant whereby the researcher attempts to surface subjective, deep issues faced by the participant in relation to the phenomenon being studied. Similarly, Patton (1990) describes phenomenology as a theory that perceives meaning in the structure and essence of an experience of a particular phenomenon by certain people. Accordingly, a phenomenological approach to qualitative research was best suited for this study, as it allowed me to explore the lived experiences and perceptions of the participants' occupational adaptation while placing their subjective experiences of long- term hospitalisation at the forefront of the study.



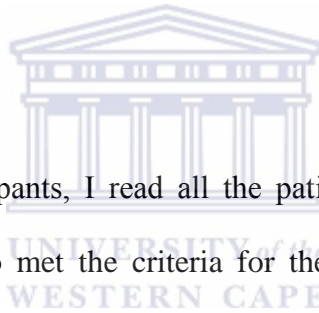
### **3.6 PARTICIPANT SELECTION AND RECRUITMENT**

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The aim of this study was to explore how adult MDR- TB patients who undergo long- term hospitalisation perceive their experience of occupational adaptation. A qualitative research approach was used because it would provide me with a thick, in depth description of the meaning that participants derive from their occupational adaptation thus a small number of participants was adequate for this purpose (Babbie and Mouton, 2001). Purposive sampling was used in this study as it allowed for the selection of participants based on “the researcher’s own knowledge of the population, its elements and the nature of the research aims” (Babbie & Mouton, 2001: 166) and assisted me to select participants who fit

specific criteria (Henning et. al., 2004). Consequently, four participants were selected to participate in this study based on the following criteria:

- Participants had a diagnosis of MDR- TB.
- Participants had been hospitalised for a period of at least 4 months.
- Participants were able to communicate effectively and express themselves adequately in English or Afrikaans.
- Participants were literate in order to be able to write in their diaries.
- Participants were in the adult stage of development.
- Two males and two females were selected to participate in the study so that the experiences and perceptions of both genders were equally represented.



Before recruiting participants, I read all the patients' folders in the MDR- TB wards to determine who met the criteria for the study. Once I identified the patients who met the criteria, I approached them individually. I provided them with an information sheet (Appendix 3), explained the purpose of the study and the role they would play and invited them to participate. Initially six patients agreed to participate but two male participants withdrew before data collection began. The following table provides a description of the study participants.

	Age	Gender	Duration of Hospitalization	Diagnosis	Additional information:
<b>Participant 1</b>	20 years old	Female	21 months	MDR TB	Participant was admitted to the hospital previously for MDR - TB. Mother of a three- year old son. Participant's mother also has MDR TB. Highest standard passed is Std 8 (Grade 10), previously employed.
<b>Participant 2</b>	45 years old	Male	5 months	MDR TB	Divorced, 1 child, history of Substance abuse. Participant was admitted to the hospital previously, defaulted TB Treatment. History of incarceration. Previously employed as a factory worker in knitting factory and worked as a security guard.
<b>Participant 3</b>	38 years old	Female	6 months	MDR TB	Married, homemaker, mother of a 16-year-old daughter, previously admitted for TB, experienced severe side effects of the TB Treatment. Good support from family.
<b>Participant 4</b>	35 years old	Male	18 months	MDR TB	History of Substance abuse, previous incarceration, no support from family. Qualified electrician and plumber.

*Table 1: Description of Participants.*

### **3.7 DATA COLLECTION METHODS**

Qualitative methods of data collection were utilised in this study. The three most common qualitative data collection methods are focus groups, interviews and participant observation (Mack et. al., 2005). Other qualitative data collection methods include the use of personal documents such as diary entries, reflective journals and document reviews (Atkinson & Coffey, 1997; Eagle, Hayes & Sibanda, 1999 and Babbie & Mouton, 2001). In this study, I utilized semi-structured interviews, diary entries by the participants, participant observation and a focus group for the purpose of data collection.

#### **3.7.1 Semi -Structured Interviews**



Interviews aim at determining what participants think, know and feel. More than one interview is generally required to gain such an understanding (Henning et.al. 2004). Semi-structured interviews are in-depth interviews conducted between the researcher and a single research participant and allow for a more natural way of interacting (Terre Blanche & Kelly, 1999). During semi-structured interviews a set of predetermined questions may be used to guide the interview process but the interviewer begins the interview with an open-ended question and picks up on cues from the participant's response to ask further questions (Terre Blanche & Kelly, 1999). An interview guide can thus be used in a flexible manner. According to Boyce and Neale (2006), the main advantage of interviews is that they provide much more thorough data than other data collection methods. In listing the disadvantages of interviews they explain that the process of conducting,

transcribing and analysing interviews can be very time consuming and due to the small number of research participants, results cannot be generalized.

Interviews were applicable to this study as they allowed me to interact with the participants in a natural and informal way. By conducting the interview in a familiar setting where participants felt comfortable and were not intimidated by the experience, I was able to elicit rich information from the participants regarding their subjective hospital experiences. The participants were also familiar with me as a staff member. Also, as I already established a relationship with them, they were comfortable to speak to me about their experiences at the hospital. I conducted a semi- structured interview as well as a follow- up interview with each participant in this study.

#### **3.7.1.1 Initial semi- structured interview**

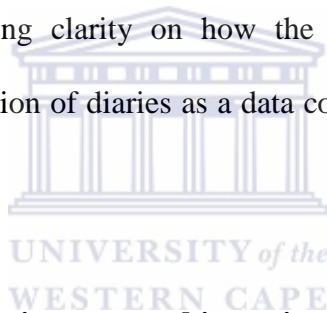
An initial interview was conducted with each participant in English and/or Afrikaans depending on the language preference of the participants. The purpose of the initial interview was to get a general overview of the participants' occupational lives while in hospital. The initial interviews allowed me to explore how the participants perceived themselves as well as the meaning and purpose that they attached to their occupations.

During the initial interview I reviewed the study purpose and process with the participants. I also clarified the meaning of the term occupation with them as well as what was expected throughout the research period. The interview served as an initial exploration of their experiences of long- term hospitalisation. Making use



of an interview guide (see Appendix 3), the questions posed pertained to the occupations they engaged in at the hospital and the meaning and purpose that they derived from these occupations. I further questioned if and how their occupations have changed since being hospitalised and whether there were any occupations they would have liked to engage in but could not, due to being hospitalised. The initial interviews lasted approximately one hour each and were audio taped and transcribed verbatim. The transcripts were translated from Afrikaans to English where necessary. The interviews were then labelled and dated.

In addition, the initial interview served the purpose of issuing the diaries to the participants and providing clarity on how the diaries were to be used. A description of the utilisation of diaries as a data collection method in this study is provided below in 3.7.2.



### **3.7.1.2 Follow-up semi- structured interview**

The follow-up semi structured interviews was conducted with each participant two weeks after the initial interview. The purpose of the follow-up interview was to gain a deeper insight into participants' experiences of occupational adaptation while in hospital. Data collection revolved around gaining a deeper understanding of participants' perceptions of themselves and the meaning and purpose they attached to their occupations. In addition, I explored the participants' perspectives on their occupational competence. An interview guide (Appendix 4) that addressed their occupational engagement was utilized. The questions for the follow-up semi- structured interviews were based on data that emerged from the

initial interviews as well as the diaries. Interviews were conducted in English and/or Afrikaans depending on the language preference of the participant. The data recorded in the semi structured interviews were then transcribed verbatim and translated from Afrikaans to English where necessary.

### **3.7.2 Diaries**

Babbie and Mouton (2001) suggest that diaries allow participants to express thoughts and feelings they might not express publicly, while Corti (1993) and Jacelon (2005) states that diary entries can be used to supplement interview data to enrich the data. Walliman (2006) also states that diaries are useful tools for the collection of information regarding personal interpretations of experiences and feelings. According to Massey and Lewis (2004) the main advantage of using diaries as a data collection method is the fact that it is complimentary to other sources of data. In addition, they state that a diary allows the participant to reflect on events as they occur as opposed to relying solely on memory. Massey and Lewis (2004) also reflect on the disadvantages of using diaries in research. For instance, some participants may be unwilling to complete the task of writing in their diaries while others may be unable to complete the task due to varying literacy skills or impairments e.g. visual impairments.

Diaries were utilised as a data collection method in this study, as it allowed me to explore how the participants perceived themselves as occupational beings as well as the meaning and purpose they attached to their occupations. Diaries were further utilised to supplement the data that was gathered in the interviews. All the

participants were willing to keep a diary and they were able to read and write. Each participant was issued with an A4 book and a pen and was requested to write a daily diary for a period of seven days. Instructions for keeping the diaries were inserted on the inside cover of the A4 book and contained guiding questions (see Appendix 5) to assist in the conceptualisation of their thoughts. One diary was issued to each of the four participants and all of them returned the diaries to me after the seven day period. The length of the diary entries as well as the quality of the content varied among the participants. Some participants merely reported on how they spend their days, while others elaborated on their thoughts and emotions when reflecting on their occupational engagement thus providing richer data.

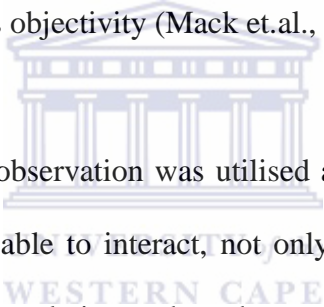
### **3.7.3 Participant Observation**



Participant observation allows the researcher to become an instrument of observation by witnessing first hand how people act within a particular setting (Henning et.al., 2004). In addition, participant observation allows the researcher an opportunity to gain insight into contexts, relationships, behaviour and information that might otherwise remain unknown (Mack et. al., 2005). According to Babbie and Mouton (2001) there are two types of observation that can be used in qualitative research i.e. participant observation and simple observation. In simple observation the researcher conducts observation from outside whereas with participant observation, the researcher becomes a member of the group being studied. Walliman (2006) states that photographs, videos or sketching can be used in conjunction with observation to supplement data and

allows the researcher the opportunity to document events being observed as it occurs.

One of the advantages of participant observation is that being a member of the group does not mean that you have to participate in what the people being observed do, but it allows the researcher to interact with them while they do it (Babbie and Mouton, 2001). According to (Mack et.al., 2005) there are three core disadvantages to participant observation i.e. it can be very time consuming, documenting observations can be difficult as it relies heavily on memory and personal discipline from the researcher is an essentially subjective exercise, whereas research requires objectivity (Mack et.al., 2005).

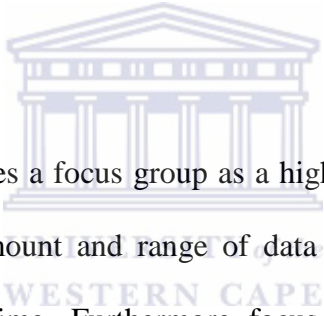


In this study participant observation was utilised as an additional data collection method. I was therefore able to interact, not only with the participants but also with the greater patient population and to observe their occupational engagement within their natural setting. Photographs were taken to document my observations of the participants' occupational engagement. The photographs further provided a record of participants' reactions and/or expressions related to the meaning and purpose they derived from this engagement.

Participant observation took place over a period of one week. I spent approximately two hours a day observing the participants and broader hospital patients' occupations. I observed patients at various intervals thereby allowing me to observe the patients' occupational repertoire as it occurred throughout the day. Appendix 7 provides a tabulated description of the participant observation as it

occurred in the study. As the participants were familiar with me as a staff member, I interacted with the patients during the participant observation process by conversing with them about their occupations as I observed them. This interaction allowed me to gain a deeper understanding of the meaning and purpose they attached to their occupational engagement. After the seven days of participant observation were completed, I developed the photographs that I took during this period and wrote a reflective note on the back of each. These notes together with the field notes taken during my observations constituted the data derived from participant observation.

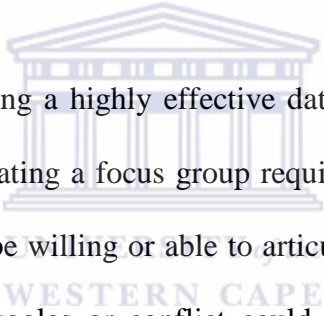
#### **3.7.4 Focus Groups**



Robinson (1999) describes a focus group as a highly effective technique for data collection in that the amount and range of data is greater as more people are interviewed at the same time. Furthermore, focus groups can help facilitate more ‘forbidden’ topics, as a less inhibited participant may break the ice and the group dynamic may stimulate a discussion or reactions from other participants (Mack, et. al., 2005; Robinson, 1999). The main strength of focus groups is that they allow researchers to distinguish similarities and differences in participants’ opinions and experiences through group interaction (Ashbury, 1995; Kitzinger, 1995) thereby allowing them to examine different perspectives as they operate within a social network (Barbour and Kitzinger 1999).

A focus group was applicable to this study as it allowed me to further investigate how the participants perceived their occupational identity as well as how they

perceived their occupational competence while undergoing long-term hospitalisation. All four of the participants participated in the focus group. During the focus group I was able to draw on similarities of the participants' experiences of long-term hospitalisation and the affect it had on their occupational engagement and role performance. I was able to elicit information regarding engagement in specific occupations during the focus group that I was unable to do in the interviews because certain participants' openness made it easier for others to share their thoughts and experiences with the rest of the group. I was also able to identify differences in their perceptions of specific occupations and their influence on their occupational competence.



Despite focus groups being a highly effective data collection method, Robinson (1999) asserts that facilitating a focus group requires considerable expertise; that all participants may not be willing or able to articulate their thoughts in the same way and that power struggles or conflict could occur within the group which could detract from the interview. In this study, the focus group discussion elicited a debate among the research participants regarding certain issues. This, however, resulted in richer data as I was able to elicit various viewpoints on specific topics without creating conflict within the group.

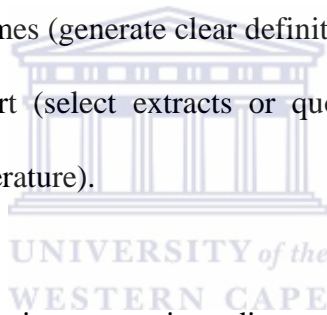
For the purpose of this study photo elicitation was used as a technique to elicit a deeper discussion in the focus group. Hurworth (2003) suggests that the use of photographs during interviews may trigger memories and lead to new perspectives and explanations. In addition, photo elicitation delves deeper into the human consciousness than interviews or focus groups do independently and are therefore

able to elicit longer and more comprehensive interviews (Harper, 2002). The photographs that were used in the focus group were taken by me during participant observation and illustrated the participants' and the greater patient population's occupational engagement in the hospital. Participants were asked to select the occupations as depicted in the photographs that they could identify with. This triggered their memories in relation to their subjective experiences of occupational engagement while being hospitalised thereby allowing them to express their views and opinions based on their personal experiences.

I selected 20 photographs for the purpose of photo elicitation. Appendix 7 provides some examples of the photographs that were used. The photographs were selected based on an analysis of the occupational categories that emerged from the participant observation. All participants were given an opportunity to select five photographs that they identified with. Each participant was then asked to share their thoughts regarding the photographs they selected with the rest of the group. The other participants were then allowed to express their thoughts and/or ask questions regarding the photograph that was presented to them. This allowed me to establish how the participants perceived the images portrayed in the photographs and to further explore their subjective experiences of long-term hospitalization and occupational adaptation. Once the focus group was completed all recorded data was transcribed verbatim, dated and labelled.

### **3.8 DATA ANALYSIS**

In this study thematic content analysis as defined by Braun and Clarke (2004) was utilised to analyse the data. According to Braun and Clarke, thematic analysis is defined as a method for data analysis by way of identifying, analysing and reporting ‘themes’ within the data. They describe thematic analysis as consisting of six phases namely, familiarising yourself with the data (transcribing data, reading through transcripts), generating initial codes (coding interesting data relevant to the research question), searching for themes (collating and categorising data), reviewing themes (check whether themes work in relation to coded data), defining and naming themes (generate clear definitions and names for each theme) and producing the report (select extracts or quotes from the data relating to research question and literature).



All data sources i.e. interview transcripts, diary entries and fieldwork notes from the participant observation were read and colour coded. The codes that emerged from each data source were then grouped to form categories. Themes emerged from these categories based on similarities in the data. I then analysed the themes and attached meaning to them based on published literature that supported or contrasted with the findings of this study.

### **3.9 RIGOUR AND TRUSTWORTHINESS**

Aroni et.al. (1999, cited in Tobin and Begley, 2006) state that rigour determines the integrity, competence and legitimacy of a research project. According to



Babbie and Mouton (2001) qualitative researchers make use of different techniques to ensure the trustworthiness of their findings namely credibility, transferability, dependability and confirmability.

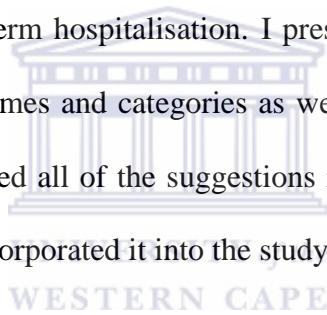
### **3.9.1 Credibility**

Credibility can be achieved through prolonged engagement in the field, constantly pursuing interpretations of data in different ways, triangulation, referential adequacy (recording interviews on tape/ video), peer debriefing, and member checks (Babbie and Mouton (2001). I ensured the credibility of this study through triangulation, member- checking and referential adequacy.

Triangulation can be employed in both quantitative and qualitative studies as a means of broadening its data sources thereby offering a deeper, more comprehensive result (Tobin and Begley, 2004). Babbie and Mouton (2001) indicate that triangulation is the application and combination of several methodologies in a research study where data is collected from different sources, while Guion, Diehl and McDonald (2002) state that there are five types of triangulation. The five types of triangulation are data triangulation (using different sources of data), investigator triangulation (using more than one researcher), theory triangulation (using a multiple set of professional perspectives to interpret a single set of data), methodological triangulation (using both qualitative and quantitative methods in the study) and environmental triangulation (using different locations, settings or other key factors related to context e.g. time of day, day of the week or season). In this study I employed data triangulation where the semi structured interviews constitute the first source of data, diaries the

second, participant observation, including the photographs was the third and the focus group the fourth source of data. Using different data sources resulted in richer, more in depth data being elicited in this study.

Member checking entails consultation with the participants to confirm whether the research findings are an accurate reflection of their experiences and perceptions (Babbie and Mouton, 2001). During the analysis phase I facilitated an additional focus group with all four participants for the purpose of member checking to verify whether the data had been interpreted accurately and whether the findings of the study is a true reflection of their experiences of occupational adaptation while undergoing long term hospitalisation. I presented and discussed my initial interpretations of the themes and categories as well as possible conclusions with the participants. I recorded all of the suggestions regarding the data made by the participants and then incorporated it into the study.



Referential Adequacy entails using various materials to document findings (Babbie and Mouton, 2001). For the purpose of this study, the interviews, focus groups as well as the member- checking group were audio- recorded using a dictaphone. I also made use of Photographs to document my observations during the participant observation.

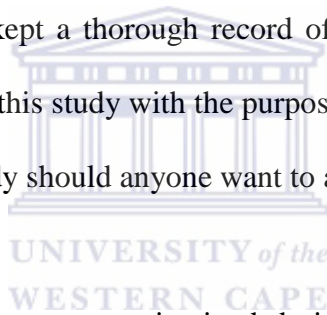
### **3.9.2 Transferability**

Transferability is achieved through providing a thick description of data as well as purposive sampling (Babbie and Mouton, 2001). In this study I recruited the

participants using pre- determined criteria and I was able to use multiple sources of data to provide an in depth description of the participants' experiences of occupational adaptation while undergoing long- term hospitalisation.

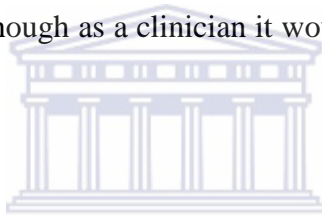
### **3.9.3 Dependability and Confirmability**

Dependability includes auditing of data while confirmability incorporates maintaining an adequate audit trail i.e. raw data, data analysis products, evidence of themes that were developed, findings and conclusions, and materials related intentions and dispositions including personal notes and expectations (Babbie and Mouton, 2001). I have kept a thorough record of the research process and data analysis trail throughout this study with the purpose of ensuring dependability and confirmability of the study should anyone want to audit the data.



In addition, personal notes were maintained during the research process for the purpose of reflexivity. Eagle, Hayes and Sibanda (1999) suggest that reflexivity allows the researcher to acknowledge her role in the research. Reflexivity entails depicting the growing “ideas, assumptions, hunches, uncertainties, insights, feelings, and choices the researcher makes as a study is implemented and as a theory is developed, providing means for making transparent the interpretive, constructive processes of the researcher” (Fassinger, 2005, p. 163), while reflexive bracketing allows the researcher to identify and ‘bracket’ any potential bias so that they influence the research minimally (Ahern, 1999).

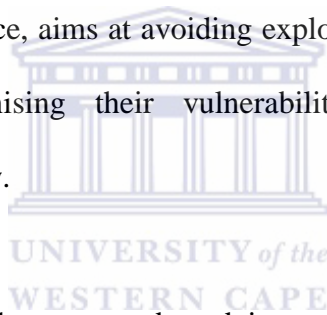
Acknowledging thoughts, feelings, insight and perceptions and bracketing issues that would result in any potential bias that arose from me being employed as a clinician at the hospital were an important process in being reflexive in this study. One of the issues I had to contend with were the fact that I constantly had to reflect on my role as a researcher and not overstep the boundaries in terms of my inherent desire to respond therapeutically to what the participants were expressing. For instance, the participants were of the opinion that by expressing themselves to me, I would be able to provide an immediate solution to their problems which I was unable to do. Also, during the participant observation, I observed certain high-risk behaviours first hand, but was unable to address these issues as a researcher although as a clinician it would have been my responsibility to report it.



I maintained reflexivity throughout the research process by documenting my observations, thoughts and perceptions during the research process in a journal and by having debriefing sessions with my research supervisor. These sessions as well as the journal entries allowed me to reflect on the research process and to maintain objectivity as a researcher. During the analysis process I constantly had to reflect on whether or not I was bringing my own opinions and expectations to the forefront of the research or whether my findings were a true reflection of the participants' experience. By meeting with my research supervisor and discussing my findings with her at length, I was able to bracket issues that were a result of my preconceived notions of the participants' experiences.

### 3.10 ETHICAL CONSIDERATIONS

According to Orb, Eisenhauer and Wynaden (2001) there are three ethical principles that researchers need to be aware of namely autonomy, beneficence and justice. The first principle, autonomy, focuses on the research participants' right to be informed about the study and freely decide whether they wish to participate in the study or not. This principle is also referred to as informed consent. The second principle, beneficence, focuses on being aware of the potential harm that could occur if the participants' identities are revealed and ensuring that confidentiality and anonymity is maintained throughout the research process. The third principle, justice, aims at avoiding exploitation or abuse of the research participants by recognising their vulnerability and acknowledging their contributions to the study.



To ensure that this study was conducted in an ethical manner, permission to conduct the study was sought from the medical superintendent at the Hospital. The participants were informed about the nature and significance of the study and informed consent was sought from all the participants in the study. The consent form (see Appendix 8) and the information letter (see Appendix 9) were translated into Afrikaans. Participation in the study was voluntary and participants were informed of their right to withdraw their participation at any time without being penalised for not participating. The confidentiality of participants was maintained by ensuring that all audiotapes and other data were stored in a locked cupboard that only I had access to. Anonymity was maintained in this study and any reports or publications that may result from it will not contain information that may

identify participants, or the hospital and staff. The researcher has ensured that all participants are aware of their right to access the findings once the study is complete.

### **3.12 CONCLUSION**

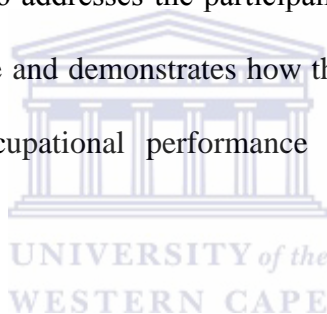
This chapter provided a detailed description of the research setting including the general appearance of the hospital and the intervention programme currently offered. In addition, the interpretivist research paradigm was discussed and applied to this study. The utilization of the qualitative research approach and the phenomenological research design was highlighted in terms of how its principles were applied in this study. Finally, I discussed how rigor, trustworthiness and ethical standards were ensured in the study. The next chapter provides an analysis of the research findings where specific trends and patterns that emerged from the data will be presented as themes and related categories.

## CHAPTER 4

### STUDY FINDINGS

#### 4.1 INTRODUCTION

In this chapter the findings of the study are presented. Table 2 provides an outline of the themes and categories that emerged from the analysis of the data. Theme one describes the participants' perceptions of themselves and their occupational identity, while theme two addresses the participants' perspectives regarding their occupational competence and demonstrates how the participants responded to the constraints to their occupational performance that they experienced in the hospital.



THEMES	CATEGORIES
1. We are Occupational Beings	<ul style="list-style-type: none"><li>• Who we are is connected to what our basic needs are</li><li>• Birds with broken wings cannot fly</li></ul>
2. Overcoming constraints to occupational competence	<ul style="list-style-type: none"><li>• With God's help we can</li><li>• Adapting to environmental constraints</li><li>• Adapting to occupational demands</li></ul>

*Table 2: Themes and categories*

## **4.2. THEME 1: WE ARE OCCUPATIONAL BEINGS**

This theme highlights the participants' perceived occupational identity in relation to how they viewed themselves firstly as human beings and secondly as occupational beings. The theme is sub-divided into two categories namely: Who we are is connected to what our basic needs are and Birds with broken wings cannot fly.

### **4.2.1 Who we are is connected to what our basic needs are**

All the participants expressed their views of themselves in relation to their perceived needs. While having a diagnosis of MDR TB itself did not necessarily change their views of themselves, the participants stressed that undergoing long-term hospitalization infringed their basic human needs as they felt that their needs were not met. The participants stated that hospitalization impacted their need for freedom, autonomy and dignity.

They all felt that the hospital rules and regulations restricted them and stripped them of their freedom. They likened their feelings of being trapped to that of being incarcerated.

*... you've been taken out of society and put into a certain place without a cut off period...I mean, that's like taking me, putting me in and locking the door...they mustn't come and lock me up; I mean that is like putting us in prison. (Participant 4)*



*It is not nice to be locked up. A person also needs their freedom.*

*(Participant 3)*

The participants felt that the hospital rules around infection control constrained them and infringed their autonomy. They felt that being hospitalized already inhibited them, thus being confined to a single ward was very distressing to them.

*They restrict you. "You must tell me if you go out". Oh no, I can't handle such things. (Participant 1)*

*We are already in hospital ... why do they want to lock us up?*

*(Participant 3)*



*...that's where the whole fuck up [sic] comes in where you've been put in a cell type thing, you stay there you do what I say, finish and klaar. (Participant 4)*

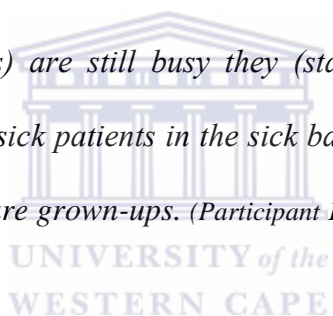
The participants further expressed that they were not treated as adults as they had no voice when it came to issues that affected them.

*We are not being allowed to be an adult. Because I think it is, being an adult you can make choices, but here your choices are being made for you. I'm not a child... Why must my freedom of choice be taken away? (Participant 4)*

*I think...if they implement something at the hospital, we know we must be here, but before they implement something, get the patients together and have a meeting and ask them, “how do you feel about this? Are you satisfied?” (Participant 2)*

With regards to their dignity, the participants felt that they were not respected at the hospital. They expressed that they were stigmatized for having TB as they were ill- treated and looked down upon.

*While they (patients) are still busy they (staff members) say “come, come, come” to the sick patients in the sick bay, hit them. They are not their children, they are grown-ups. (Participant 1)*



*The other patient, I felt so sorry for her because she was unable to help herself ... and she was half naked and about to expose herself to the world. (Participant 3)*

*I am not a bad person because I got TB and I landed up in hospital. People become judgmental; they think you are a dirty piece of shit that's why you have T.B. That's not why we have T.B. It makes me feel kak [sic]. And that's what makes you rebellious. You get treated like a piece of nothing, a piece of worthless nothing. (Participant 4)*

#### 4.2.2 Birds with broken wings cannot fly

In addition to their need for freedom, autonomy and dignity, the participants expressed a need for occupational engagement.

*As long as I am not working, I have nothing. (Participant 1)*

*You want to be like a female at the end of the month, you want to go shopping...you want to be part of life. (Participant 4)*

The participants spoke about the losses they experienced as a result of their hospitalization and how this affected their occupational engagement. They indicated that their hospitalization made them feel despondent as they were unable to perform the occupations that they would normally perform in their home environment.

*You sit and think perhaps of home. If I was working today, on Friday I would get paid, but look where I am sitting now. And Friday nights I think, yes, I would have been at a club, dancing, but look where I am sitting now. (Participant 2)*

*you get time for your lock down, and you get time for your free walk, you get time when you can eat, you get time when you must go and shit. You have all of those things you know and then, it builds like a lot of different emotions, and a lot of different thoughts. (Participant 4)*

*Sometimes when there is no one around, then I sit by the window. Then that is the time when I just feel like...I start crying. (Participant 3)*

They felt that they were unable to fulfil their roles as parents or caregivers and that they missed out on valuable opportunities to engage with their families. Not being able to fulfil their occupational roles left a void in their lives.

*He is my child...I am still his mother... I brought him into this world and I must look after him. You miss out on everything, crèche concerts, everything, I miss out on everything... (Participant 1)*

*It hurts because you know there are times when she is difficult, you know teenagers. Then I feel like I am not there to help or to talk to her, to help her to do the right thing or give her a hug to say everything is going to be ok. (Participant 3)*

*It's like a bird, cut his wings and throw him into a cage and he can't fly anymore like he used to. (Participant 4)*

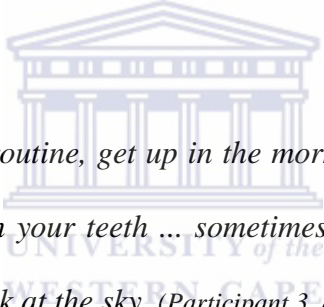
The participants further stated that due to the lack of occupational choices that was available to them in the hospital they experienced a high level of boredom.

*You can't do everything that you want to do here...you can only watch TV. (Participant 2)*

*It bores you ten times more if you sit with a lot of time and you don't know what to do with it... Sometimes you just want to go out...and walk to the beach. (Participant 4)*

*Weekends when we don't go home I think it is boring for me, doing nothing ... (Participant 3, diary)*

The participants reported that they mainly engaged in monotonous routines of activities of daily living and leisure activities in the hospital.



*patients do the same routine, get up in the morning, take tablets, have breakfast, wash, brush your teeth ... sometimes I read my bible or sit by the window and look at the sky. (Participant 3, diary)*

*I eat ...and when I'm done eating I lie down. Or I read a book, or I sleep. (Participant 2)*

During participant observation I observed that the female patients preferred to engage in structured activities like sewing and beading, while the male patients preferred unstructured activities such as playing cards or dominoes, and watching television. I also observed that the participants' utilized the bigger part of their days to socialize with each other. The participants confirmed that they found pleasure in socializing and interacting with other patients.

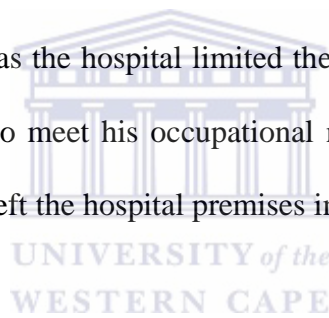
*I walk around talk to people... sometimes to the hospital staff... make jokes with them...takes my mind off things... (Participant 3)*

*I chat to people every day that is what I do. (Participant 2)*

*Today was a very nice day. I chatted to some people, we laughed...*

*(Participant 3, diary)*

Participant 2 stated that as the hospital limited the interaction between males and females he was unable to meet his occupational need for sexual expression and therefore he sometimes left the hospital premises in order to satisfy this need.



*I just feel that if I want to be with a girl, or if I like that girl then I will be with her...or sometimes I leave the premises... when I return I feel better. (Participant 2)*

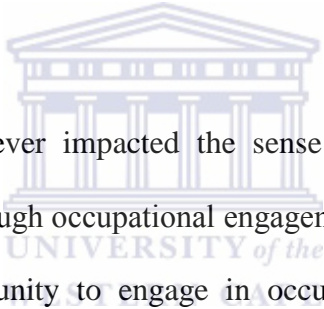
The participants further expressed that they preferred to participate in activities that they enjoy doing and that had a sense of meaning and purpose.

*How can I put it ... I enjoy doing things with my hands... I want to make nice things...we must do it ourselves, earn money for ourselves, and then you (OT) can get a percentage. Then we can buy nice*

*things. (Participant 1)*

*Maybe if you look at the bigger aspect...tell the guys listen here there's an old house fix it up.... Whatever happened to the garden, a simple thing like that will make a difference. Let the men be creative. (Participant 4)*

*I am lying in bed, thinking I am going to get up and get our medication cards ready and put it on the table so it could be ready...to make it easier for the (nursing) sister. (Participant 3)*



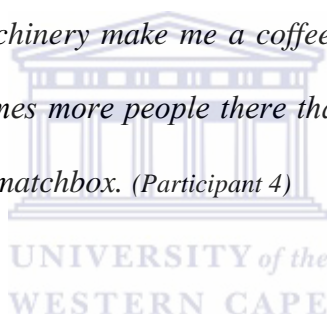
Being hospitalized however impacted the sense of meaning and purpose the participants' derived through occupational engagement. They felt that they did not always have the opportunity to engage in occupations that they regarded as meaningful as their occupational choices available did not always meet their interests.

*... the stuff that gets done, not everyone is interested in. You have got a small variety of things to do ... for me now sitting at OT and weaving beads or making a little box, there's no interest in there, no satisfaction for me. (Participant 4)*

*You can't do everything that you want to do here ... you can only watch TV. (Participant 3)*

Participant 4 felt that the activities that were available at the hospital did not meet the level of skill that he possessed. This affected his morale as he did not feel challenged. He was of the opinion that if the patients felt that they were presented with a challenge it would motivate their active participation in the activities.

*But what I mean, here go and make me a necklace... there's no challenge ... I am a qualified electrician, I am a qualified plumber... do you think I want to come sit here sit in OT making necklaces or making beads?... If you give a guy a piece of plank and say here is the wood, here is the machinery make me a coffee table I guarantee you there would be ten times more people there than telling me, there's a matchbox make me a matchbox. (Participant 4)*



#### **4.3 THEME 2: OVERCOMING CONSTRAINTS TO OCCUPATIONAL COMPETENCE**

This theme highlights the constraints that the participants experienced in their attempts to achieve occupational competence in the hospital environment and demonstrates the factors that supported the participants' attempts to overcome these constraints. The theme is sub- divided into three categories namely: With God's help we can, Adapting to environmental constraints and Adapting to occupational demands.

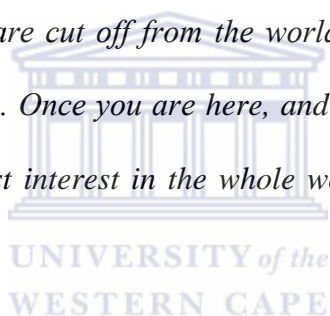


### 4.3.1 With God's help we can

The loss of support that the participants experienced due to their hospitalization was a key concern for them. During the focus group they articulated that their isolation from the outside world contributed to the lack of meaning and low morale that they experienced.

*To just sit like that every day you will go mad...you can't talk to anyone because they are too sick or they just want to stay in bed. (Participant 1)*

*....you feel as if you are cut off from the world...that is also part of a person's frustrations... Once you are here, and you start feeling lonely, you basically, you lost interest in the whole world, in life, you know... (Participant 4)*



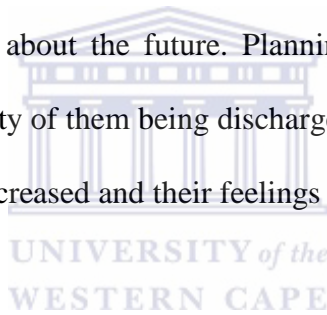
The participants articulated that in an attempt to raise their morale they made an effort to form supportive friendships with other patients in the hospital. These bonds however ended abruptly when their friends were discharged from hospital or in the event of their friends passing away. This further impacted their morale negatively as the comfort that these relationships provided was lost.

*There is little support systems here, and the little bit that there is, is lost within a couple of weeks and then that chap is all by himself... That is not lekker, I mean now that, that is heart-breaking, you know. Because some people you get very attached to, there is some people you get really,*

*really attached to because there is no one else, and somehow that support structure is gone.... it's not a nice day, it's like having a funeral...*  
(Participant 4)

*That whole day (after a patient in the ward passed away)...I just felt like I wanted to cry... I just wanted to be alone thinking that I don't want that to happen to me. (Participant 3)*

During the focus group discussion participants further articulated that their lack of motivation and drive caused them to have difficulty with setting goals as they felt anxious and ambivalent about the future. Planning for their future was further impacted by the possibility of them being discharged due to treatment failure, thus their sense of purpose decreased and their feelings of anxiety escalated.



*What if we plan ahead and then they tell us we won't get better.*  
(Participant 3)

*I'm not saying that everything is out of my hands, but I can't do anything now. (Participant 1)*

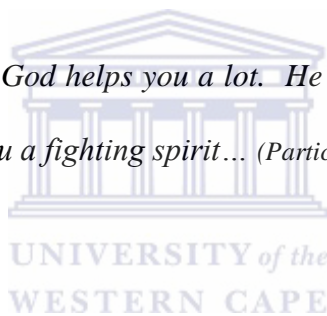
*... you come to a certain point in your time of hospitalizing, whatever, you come to a certain point that you just switch off and you put everything on hold...you can't make a definite plan...because you never know what tomorrow brings. (Participant 4)*

There were instances where they described their search for meaning and purpose as positive. This related to the way in which their spirituality assisted them to cope with their illness and hospitalization. The participants related the sense of meaning that they derived from occupational engagement to their belief that being in hospital was part of God's purpose for their lives. This belief facilitated a change in their attitude towards their participation in the programme.

I ask God to keep me strong. (Participant 1)

*I feel like when I take my problems to the Lord that is the only time I can get through it. (Participant 3)*

*Your connection with God helps you a lot. He gives you the strength that you need; He gives you a fighting spirit... (Participant 4)*



#### **4.3.2 Adapting to environmental constraints**

During the focus group discussion the participants stated that they found it difficult to adapt to the hospital environment and discussed this at length. They felt that as the staff was not supportive of them they did not feel motivated to participate in the programme.

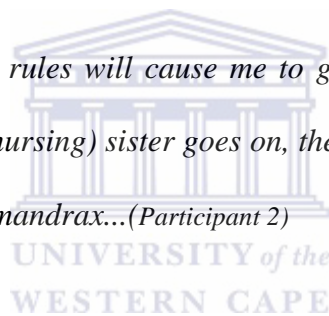
*Not if they break you down like that, because then you cut yourself off from everything ... the staff is the reason the people don't want to come to OT. (Participant 1)*

*Yes, and then if you come there them the men say, no, fuck [sic] OT! The (nursing) sister already treats us like this. (Participant 2)*

*You just sit back, come hell or high water you feel nothing, and at the end of the day you feel for yourself nothing. (Participant 4)*

At times their struggle to adapt to the environment resulted in high-risk behaviour. The participants saw this as a coping strategy as well as a form of rebellion against the hospital system.

*Now see, all of these rules will cause me to go back to my old habits again...the way that (nursing) sister goes on, the other day, I went to buy a button and smoked mandrax...(Participant 2)*



*Now what happens? They can't get rid of their frustration and so they take it out on each other. That's why there are so many fights, so many drinking, so many drug abuse, so many jumping over the walls all that crap...When I roll my dagga joint I see an escape route for my emotions. Then whatever I felt this morning, it goes away later on. (Participant 4)*

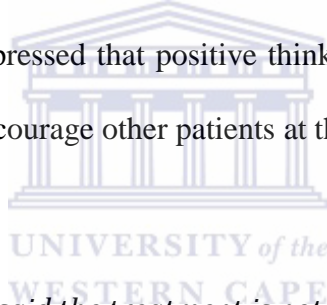
While the participants found the hospital environment to pose various challenges, there were instances that they were able to overcome these challenges. Being able to draw on a support system was an important factor that contributed to this. The participants expressed that the support they received from their family and friends

made it easier for them to cope with the challenges they faced at the hospital.

*you want that motherly love, that fatherly love, that brotherly love...that's normal... (Participant 4)*

*When I got here, for those four months, my father came every week on a Saturday for those four months because I was not used to the people. (Participant 1)*

The participants reported that they relied on personal resources to cope with their hospitalization. They expressed that positive thinking enabled them to cope with their prognosis and to encourage other patients at the same time.



*With me, the doctors said the treatment is not working; they have to operate. I have been here for a year and eight or nine months and now I am going home. Today I have two negative cultures because I didn't listen to what they told me. (Participant 1)*

*I feel that doing my bit is not good enough. And it makes me feel shit. It makes me feel like leaving and giving up hope. Throw in the towel. But then I decide that I am not going to give in. (Participant 4)*

*I told the patient the other day...you gonna lay like this, how you gonna go home, in a wheelchair? Then you can't take care of your baby anymore? You must help yourself... (Participant 3)*

### **4.3.3 Adapting to occupational demands**

Despite the constraints they experienced, the participants came to the realization that their active participation in the hospital programme would help them to learn new ways of doing things. They reported, in the focus group discussion, that their participation in the groups assisted them to adapt to the demands of the group, thereby learning to communicate and express their emotions constructively.

*It is good to have a group sometimes and share your emotions. It helps express your feelings sometimes. (Participant 4)*

*The group that I was in, I learned to know everyone and we communicated well together. (Participant 2)*

The participants further reported that for them active participation implied making a concerted effort to maintain themselves and their daily routine.

*And then I lay for a few seconds and then I say no, this can't happen, I can't lay like this. And then I get up and I make up my bed and I bath and get done. (Participant 3)*

*When I looked again I was up, I made up my bed, ran my bath and took out my clothes... (Participant 1)*

*This morning I just felt to get dressed and look nice for a change, we don't have to sit in pyjamas all day just because we are sick in hospital. (Participant 3, diary)*

Some participants expressed a desire to succeed in adapting to the occupational demands that the programme presented. This was evident by the goals that they set for themselves and the feelings of accomplishment that they associated with this.



*... if I feel like I'm going to do something and I finish it then I will feel proud of myself and say that's my work, I did that, I finished that. (Participant 3)*

WESTERN CAPE

*You feel like, how can I say...I did something now. (Participant 2)*

*I was thinking of making my own beads, that's what I always wanted...  
It is a great opportunity for us to do all these things because if we leave here, back home we can do our own activities and start our own business. (Participant 3, diary)*

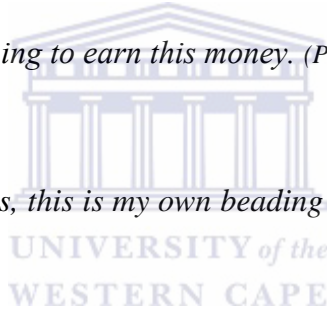
During participant observation I observed that the sense of purpose they derived through their active performance of an activity assisted the participants to adapt to the demands of that activity and to subsequently make strides towards achieving

their goals. This observation was confirmed when the participants described their skills and articulated a sense of pride in their abilities.

*I can blow-dry your hair, I can cut your hair, I can dye your hair, I can bleach your hair, roll your hair, I can do everything. I can pin your hair up, all types of things. If you want to model ... or whatever, then I'll fix your hair quickly. (Participant 1)*

*A lady at OT called me and asked me if I want to help wash the cars. At least I earned R32. So I could go and buy myself a cool drink ... u feel like...I did something to earn this money. (Participant 2, diary)*

*Ok, this is my products, this is my own beading and I am very proud of it. (Participant 3)*



#### **4.4 CONCLUSION**

In this chapter the findings of the study were presented. The process of data analysis resulted in three themes. Theme one described how the participants perceived the effects of long-term hospitalisation on their occupational identity. All the participants expressed that not having their needs such as freedom, dignity, autonomy and occupational engagement met, impacted their sense of self. The participants also expressed that they felt isolated from the outside world as a result of being hospitalised. One participant likened his experience to that of a bird with broken wings trapped in a cage. Like a bird in a cage are not able to fly, so too the



participants were unable to function like they did prior to their hospitalization, leaving a void in their lives. Theme one further highlighted the challenges that the hospital environment presented in the participants' search for meaning and purpose in their occupational engagement while hospitalised. The participants emphasized that they were not always provided with opportunities for meaningful occupational engagement in the hospital. As a result their level of motivation was low.

Theme two demonstrated the constraints to occupational performance that the participants experienced while they attempted to successfully engage in occupation while hospitalised. The participants expressed that a lack of support and their anxieties around their prognosis made it difficult for them to plan their future and to strive towards their goals. The participants stated that their faith in God was an important component of their well-being and provided them with a sense of meaning and purpose in their occupational engagement.

Theme two further highlighted that some participants engaged in high-risk activities such as substance use, as a coping strategy for long-term hospitalisation. They however identified factors i.e. setting goals, and thinking positively which facilitated their occupational performance. Finally, theme two highlighted the participants' perception that active participation in activities assisted them to adapt to the occupational demands they faced, resulting in a positive changes in their occupational performance. The following chapter will provide an in depth discussion and interpretation of the study findings based on relevant literature.

## **CHAPTER 5**

### **DISCUSSION**

#### **5.1 INTRODUCTION**

The aim of this study was to explore how adults with MDR TB experience occupational adaptation while undergoing long- term hospitalization. In this chapter I discuss the findings of the study as it relates to its objectives i.e. how the participants perceive their occupational identity, the meaning and purpose the participants assign to their occupational engagement and the participants' perspectives regarding their occupational competence at the hand of relevant literature. By drawing on the occupational adaptation frame of reference (Schkade and Schultz, 1992), I synthesise the participants' experiences of the occupational adaptation process while they were hospitalized. Finally, I discuss the limitations of the study.

#### **5.2 HOW THE PARTICIPANTS PERCEIVE THEIR OCCUPATIONAL IDENTITY**

The findings of this study revealed that when the participants were asked about themselves they referred to their needs, indicating a close connection between their sense of self and what they perceived their needs to be. The findings showed that the participants' potential to satisfy their needs was hampered in the hospital. The hospitalisation of MDR TB patients for at least 6 months is compulsory

(Department of Health, 2009) and it is stated that all patients have the right to human dignity, privacy, freedom of movement, trade, occupation and social security (Department of Health, 2008). The findings however revealed that the participants were of the opinion that long- term hospitalization infringed their basic need for freedom, dignity and autonomy; thus impacting their health and well-being in a negative way. This concurs with Bynon et. al. (2007) who state that despite the fact that hospitals are usually associated with the restoration of health being hospitalised can impact people's health and well- being negatively.

The findings illustrated that the participants likened the lack of freedom they experienced to that of being incarcerated as they had no control over their lives. Haney (2002) states that incarceration requires people to adapt to a harsh and rigid institutional routine where they are deprived of privacy and liberty and experience stigma and that these experiences can have long- lasting negative psychological effects on prisoners. The participants expressed that the stringency of the hospital rules and the subsequent loss of autonomy that they experienced were major contributory factors to them associating their hospitalisation with that of imprisonment. They articulated that they were not consulted over the decisions that concerned them, that the hospital staff did not support them and that they were stigmatized by the staff for being hospitalized for TB. The findings showed that hospitalisation compromised the participants' emotional well- being and thus their overall health and well- being.

These findings concur with Max- Neef's (1991) view that there is a direct link between health and well- being and human needs. He states that people can only

experience health and well-being when their fundamental human needs are met. The fundamental human needs are grouped into two categories i.e. existential and axiological and Maslow states that these needs are interrelated and interactive. He asserts that satisfying these needs should therefore be understood in terms of the deprivation of being able to satisfy needs and the potential to satisfy needs. The existential categories (being, having, doing and interacting) represent freedom and personal choice whereas the axiological categories (subsistence, protection, affection, understanding, participation, idleness, creation, identity and freedom) represent recognition and respect of certain values.

The rigidity of the hospital environment and the lack of support within the hospital and from outside the hospital deprived the participants from satisfying their fundamental needs. Their existential categories were not met due to their lack of freedom and autonomy and their ability to exercise choice and control over their daily occupations. The fact that they felt as though they were stigmatised, demoralised and misunderstood by hospital staff as well as the restrictions they faced in terms of movement around the hospital and their occupational choices and the impact of these experiences on their self identity as well as their occupational identity are a reflection that their axiological categories were not met.

The findings of this study further showed that the participants could have the potential to satisfy their human needs if the hospital environment is more conducive to this by allowing them to have more freedom and autonomy and also by showing respect and understanding towards them thereby improving general

health and well-being. WHO (1948) defines health as a state of complete physical, mental and social well-being and not merely the absence of disease. WHO (1986) further states that individuals should be able to satisfy their needs and in doing so, change or cope with their environments in order to reach this state of well-being. Understanding the link between human needs and health and well-being is therefore imperative in improving treatment adherence of TB patients and ultimately treatment outcomes.

The findings of the study additionally revealed that the participants also viewed themselves as occupational beings. The female patients in particular articulated that their identity as parents and caregivers were affected as their hospitalization prevented them from satisfying their occupational roles. Rudman (2002) states that occupation influences people's personal identity and social identity, while Kielhofner (2007) defines occupational identity as who people feel they are and wish to become as occupational beings generated from their history of occupational participation. He maintains that amongst other factors, occupational identity is shaped by people's interests, roles and routines as well as by their environmental contexts and demands.

The findings highlighted several factors that impacted the participants occupational identity for example, their inability to satisfy their occupational roles, the drudgery of their daily routines, their lack of occupational choice and their feelings of apathy towards occupational engagement due to their lack of autonomy. It can therefore be concluded that the participants had a poor occupational identity as they articulated that these factors contributed to the lack

of personal fulfilment and individuality they experienced in the hospital.

The findings clearly indicated the participants' need for occupational engagement and the positive effect that their active participation in occupation had on their sense of self. This is in line with several authors' opinions that there is a relationship between health, well-being and occupation as occupation is part of a balanced lifestyle and is a natural biological mechanism for health (Law et al., 1998; Wilcock, 1999; Rudman, 2002 and; Pentland and McColl, 2008; Hammel, 2009a).

In confirming the participants' need for occupational engagement and the influence of their lack of occupational choices on their occupational identity, the findings of this study concurs with Wilcock's (1999) synthesis of occupation as 'doing', 'being', and 'becoming'. Wilcock argues that people need to utilise their capabilities through engagement in occupations and that they should be encouraged to pursue this need in order to not only provide sustenance, survival and security, but to improve their overall health. Occupation therefore plays an important role in TB intervention and improving treatment outcomes for TB patients as it is able to assist them to find a balance while in hospital by satisfying their needs, enhancing their self-worth and redefining their occupational roles all of which has a direct impact on their health and well-being.

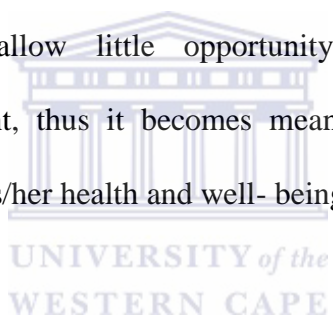
### **5.3 THE MEANING AND PURPOSE THE PARTICIPANTS ASSIGN TO THEIR OCCUPATIONAL ENGAGEMENT**

The findings highlighted several factors that influenced the participants' ability to find fulfilment in occupational engagement while in hospital for example, the monotony in their daily routine and the lack of variety in their daily repertoire of occupations were of great concern to them evident in their expressions of their occupational engagement as merely "eating, sleeping and keeping busy". They felt angry and frustrated at times, specifically with regards to their inability to have control over their occupational choices, which resulted in them finding little or no meaning in their occupational engagement. They expressed a need to engage in occupations that they found meaningful, for example going to the beach or having a braai over weekends. This point towards occupational imbalance which, according to Wilcock (1998), occurs as a result of doing too much or too little due to an inability to maintain a balance between work, rest and play.

While some participants exercised their choice by participating in activities such as baking, beadwork, playing cards or dominoes as a means of enjoyment, the participants stated that they were not always able to do activities that interested them. Moreover, the participants were of the opinion that some activities that were presented at the hospital did not meet their level of skill and did not challenge them. Regarding the arts and crafts activities presented at the hospital, the male participants emphasized that they were interested in performing activities that would match their skills, for example starting a garden or helping with renovations at the hospital as such activities would provide them with a challenge

and greater satisfaction.

Hammel (2004) argues that meaning, purpose, choice, control and a positive sense of self worth affect the way in which people experience occupation. She suggests that meaningful occupations should contribute to a person's sense of belonging and feeling valued in everyday life as well as provide hope for the future. The findings of the study support Hammel's argument in that the participants' experienced frustration and perceived that this had a negative effect on their health and wellbeing. The findings further concurs with the study conducted by Farnworth and Muñoz (2009) in which she concluded that highly structured, monotonous routines allow little opportunity or choice for purposeful occupational engagement, thus it becomes meaningless to the individual and impacts negatively on his/her health and well-being.

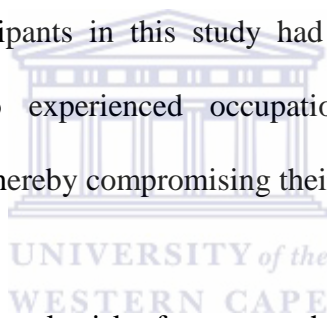


Occupational alienation i.e. the feeling that one's occupations are meaningless and unfulfilling was evident in the findings in that some participants expressed that they find little or no meaning in the activities presented at the hospital. Occupational alienation is associated with feelings of isolation and separation from a particular occupation due to an individuals' needs not being met by their engagement in that particular occupation (Wilcock, 1998). The findings additionally highlighted that the participants' experienced their daily routine as monotonous and unfulfilling as they lacked occupational choice. These findings concur with the findings of the prison studies conducted by Whiteford (1997) and Whiteford and Moulinex (1999) in which their participants' lack of occupational choice ultimately lead to boredom, de-motivation as well as a loss of skill. The



authors concluded that their participants experienced occupational deprivation as a result of their experiences in prison.

Similarly, in a study conducted by Whiteford (1997) with refugees, the findings of the study revealed that the refugees not only experienced occupational deprivation but that they also experienced occupational alienation as being out of their natural context; they could not engage in their natural occupations, resulting in a lack of meaning. Whiteford's findings are in line with that of this study's as the participants expressed that they were unable to engage in occupations that they found meaningful as they were outside of their natural environments while in hospital. As the participants in this study had similar experiences it can be inferred that they too experienced occupational deprivation as well as occupational alienation thereby compromising their health and wellbeing.



In addressing occupational risk factors such as occupational imbalance, occupational deprivation and occupational alienation several authors recommend occupational enrichment programmes. (Moulinex & Whiteford 1999; Duncan 2004; Farnworth and Muñoz, 2009). These authors state that occupational enrichment programmes aim to provide people with opportunities for autonomous choice and opportunities for active participation in programmes to support the personal development that is required for successful integration into their families and communities. Duncan (2004) suggests that through occupational enrichment personal and environmental issues that act as barriers against participation in meaningful occupations could be addressed, while Moulinex and Whiteford(1999) define occupational enrichment as the deliberate manipulation of an individual's

environment to support and facilitate meaningful occupations by addressing the needs of people who experience occupational risk.

Also, the findings strongly supported Farnworth and Muñoz (2009) argument that institutionalisation leads to people being disconnected from society and limits opportunities to develop habits and routines, which further impacts negatively on health and well-being. The participants expressed that they felt isolated from their families and society at large and that they felt lonely and unsupported as a result. This indicated that the participants could have experienced institutionalisation and is in line with Snowdown et al's (2001) view that institutionalisation results in patients becoming apathetic and passive as they lose interest in anything that is happening within or outside the institution. Both Duncan (2004) and Farnworth and Muñoz (2009) recommend the use of psychosocial rehabilitation principles when addressing occupational risk factors and implementing occupational enrichment by including topics such as adult literacy, vocational skills training, religious groups and groups focusing on community reintegration and support groups. She further states that intervention should aim at improving or maintaining daily living skills, developing and redefining roles that will support successful community integration.

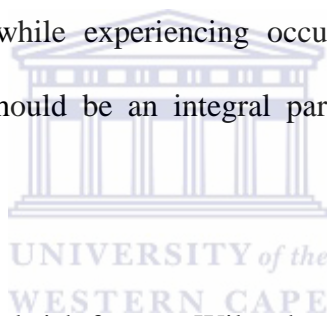
MSF (2009) asserts that there is a link between long-term hospitalisation and poor treatment adherence because specialised hospitals are situated far from the homes of the patients and that hospitalization leads to feelings of isolation and neglect amongst patients. This ultimately results in a very high default rate with some patients simply refusing to remain in hospital. Haney (2002) argues that

institutionalisation results in people becoming dependant on the institutional structure to such an extent that they forget how to use their initiative and be independent because they are denied control on a daily basis. As a result, when the structures of the institution are removed they no longer know how to do things on their own. This inability to be independent after discharge could have a negative impact on treatment adherence once a TB patient is reintegrated into their community.

According to Barros et. al. (2005) deinstitutionalisation is a process of restructuring social and institutional processes thereby allowing people or societies to take control of their own problems through exploring alternate options. In addressing intervention strategies around deinstitutionalization Bynon et. al. (2007) suggest that it is optimised when patients are involved in individual therapy as well as groups, if time is spent identifying which occupations are most meaningful to the patient, if clear goals are set, if time is spent educating patients and families about the impact of occupational disruption and if patients are able to provide feedback about their experiences within the programme. These methods will be well suited to the participants in this study as it will allow them to be involved in decision making processes regarding their occupational engagement as well as facilitate better support between them and their families.

In the participants' search for meaning and purpose the concept of spirituality emerged strongly in the findings as a strategy that they utilized to find meaning in the hospital activities and their occupational engagement. All the participants expressed that their faith played a major role in their ability to cope with their

circumstances as it provided them with a sense of hope and belief in God's purpose for their lives. This concurs with the findings of Wilding's (2007) study on the relationship between spirituality and health, which drew attention to the relationship between spirituality and occupation. The participants in her study expressed that their spirituality made it easier to engage in everyday occupations, as they felt connected to God and each other, therefore their occupations held more meaning for them. Furthermore, the findings of Wilding's study concluded that spirituality can provide people with hope, a reason to live, support and meaning in everyday occupations. Weskamp and Ramugondo (2004) however question whether it is possible for people to have hope and achieve meaning and purpose in spirituality while experiencing occupational risks. They therefore assert that spirituality should be an integral part of interventions that address occupational risk factors.



In addressing occupational risk factors, Wilcock and Townsend (2004) argue that occupational therapy intervention should facilitate occupational justice. They state that occupational justice acknowledges that needs differ from person to person and that it is aimed at understanding the meanings that occupations hold to individuals. According to Wilcock and Townsend (2004) the principles that guide occupational justice include enabling individuals' choice and control over occupational engagement, promoting the right to meaningful occupation and promoting the right to engage in diverse occupations.

Kirsh (1996) suggests the use of narratives in addressing spirituality in occupational therapy as it serves as a means of reflecting on personal experiences

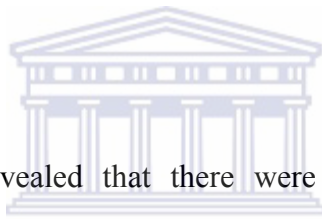
and/or difficulties associated with their condition. In constructing their story based on their experiences they acknowledge the fact that the meaning and purpose in their life is strongly linked to their life story. This in turn allows them develop their personal identity and in doing so reflect on the meaning and purpose spirituality holds for them.

#### **5.4 THE PARTICIPANTS' PERSPECTIVES REGARDING THEIR OCCUPATIONAL COMPETENCE**

According to Kielhofner (2007) occupational competence refers to the degree to which people are able to sustain a pattern of occupation that reflects their occupational identity i.e. their roles, values, self- concept and personal goals. A key finding of this study is that the participants were of the opinion that the hospital environment and the lack of opportunities for occupational engagement that were available to them affected their occupational performance in a negative way. The findings revealed that while the participants acknowledged their need for occupational engagement and the positive impact that occupational engagement had on their self- esteem, they experienced a lack of accomplishment in their occupational engagement. The findings highlighted the environmental and personal constraints that the participants faced in striving towards occupational competence as well as factors that facilitated their attempts at overcoming these constraints in order to achieve occupational competence.

The main constraint to achieving a sense of occupational competence as demonstrated by the findings was that the participants found the hospital

environment to be unsupportive towards them. Several authors name the lack of effective support systems such as those highlighted by the findings i.e. loss of support from family, friends and communities; poor client relationships, negative attitudes of health care workers as well as stigmatization of TB, as contributing factors to poor treatment adherence and ultimately the progression of the TB disease (Matebesi and Booysen, 2004; Portwig and Couper, 2006; Department of Health, 2009). According to Haney (2002) intervention in prisons should focus on providing consistent effort to encourage visitation of families and support thereby diminishing the division between the person experiencing institutionalisation and the outside world and in doing so discouraging dysfunction.



The findings further revealed that there were times when the participants' frustrations around their inability to cope with their environment manifested in high- risk behaviour such as drug and alcohol use, aggressive outbursts and absconding from the hospital to temporarily escape their circumstances. These findings support Snowdown et.al's (2001) observation that behavioural problems such as aggression and self- destruction are rife in patients who undergo long-term hospitalization. They state that such behavioural problems are usually related to the nature of the institution and encompass factors such as enforced idleness, negative staff attitudes, lack of friends, lack of possessions, loss of contact with the outside world and the general atmosphere in the wards.

According to the Ottawa Charter (WHO, 1986) context plays an important role in people's health and well- being as it is influenced by the settings of their everyday

lives. Likewise, Epp (1986), cited in Law et. al. (1998) states that a state of health is achieved when people are able to care for themselves and others, are able to make decisions and are able to take control over their life circumstances provided that the environment they live in allows for this to be attained. I can therefore conclude that TB intervention should not just focus on the bio- medical aspects of the disease but also the social aspects.

The findings further showed that the participants' uncertainty about their length of hospitalization and their prognosis were major constraints to their occupational performance as they lacked the motivation to plan for the future. The findings revealed that the participants felt that their lives were on hold while they were hospitalized and that their uncertainty around the length of their treatment and hospitalization created a great deal of anxiety within them. According to the Department of Health (2009) there is a definite link between the length of the treatment period and the efficacy of the treatment of TB patients in that patients often become de- motivated and succumb to the temptation to discontinue their therapy as a result. The Department also states that depression and a sense of disempowerment impact on the progression of TB in that it impacts how patients cope with their diagnosis. While the findings strongly supported these observations made by the Department of Health it further highlighted that the participants experienced a lack of support, low motivation and a loss of control over their futures that all contributed to their inability to set goals for themselves and consequently hampered their ability to achieve occupational competence.

The findings however also revealed that there were factors that assisted the participants to adapt to the environment and to actively perform certain occupations thereby allowing them to progress towards achieving occupational competence. The findings showed that the participants' ability to build strong bonds with each other provided them with a sense of belonging and a support system, thereby making it easier for them to cope with the hospital environment. As a result the participants in this study were able to redefine their roles within the hospital and to adapt to the environmental demands that they experienced thereby improving their motivation and occupational performance.

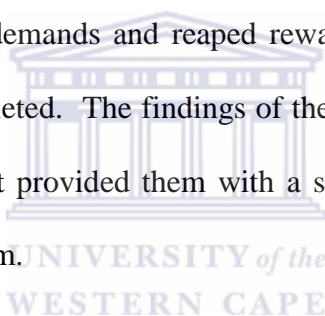
These findings concur with Hammel (2009b) who argues that where western cultures promote individualism and independence other cultures focus on interdependence and connectedness, which contributes positively to well-being. This was evident in the participants' responses regarding the positive impact their social connections at the hospital had on their emotional well-being. Hammel (2009b) therefore asserts that occupational therapy should not only focus on occupations purely in relation to self-care, work and leisure, but that they should also include prayer, caring for and supporting others and making love as meaningful occupation.

The findings illustrated that their successful attempts to adapt to the occupational demands that they experienced in the hospital enhanced the self-esteem of some participants as it allowed them to develop a sense of purpose and accomplishment. The findings showed that these participants made a concerted effort to maintain a routine and to actively participate in the activities. This aided them in striving



towards their goals and in adapting to the occupational demands of the activities presented at the hospital. For example, one participant set the goal of starting her own beading business and spent her time making beaded jewellery that she planned to sell in order to generate an income upon her discharge.

Townsend (1997) asserts that occupations have the potential to emancipate, empower and transform individuals within their environments thus allowing them to overcome barriers and to pursue aims such as health and happiness. This was evident in the findings as the participants recognised that active participation in occupation would allow them to learn new skills therefore they were able to adapt to certain occupational demands and reaped rewards such as being paid for the activities that they completed. The findings of the study also revealed that active occupational engagement provided them with a sense of accomplishment which enhanced their self-esteem.



Kielhofner (2002) describes the role of an occupational therapist in addressing the needs of clients who present with occupational dysfunction as involving an understanding of how mental, physical and environmental components contribute to the individual's occupational needs and/or dysfunction. According to Kielhofner a maladaptive cycle occurs when a person experiences repeated disorganisation, poor performance and anticipation of future failure. Dysfunction occurs because the person's ability to adapt has been challenged to the point that the demands for performance are not satisfactorily met. Kielhofner implies that poor choices, poorly organised routines and deficient skills lead to increased disorganisation and a state of occupational dysfunction. In this study the drudgery

of the participants' routine, the lack of autonomy, the experiences of occupational risk factors and institutionalisation as well as their inability to plan for their future due to uncertainty about their prognosis have resulted in occupational dysfunction in the participants.

All of the participants indicated that they were unable to fulfil their occupational roles while in hospital due to the constraints they experienced at the hospital. Haney (2002) argues that the effects of institutionalisation often only surface once the person has returned home. For example, parents who return home after being institutionalised are often still dependant on the structures of the institution and still have that "over- control" of their emotions which result in social isolation. They also struggle to make their own decisions and therefore struggle to adapt and build relationships with their children and organise their children's lives as they have an internal disorganisation. Haney (2002) recommends that therapeutic programmes should allow life in the institution to replicate normal life as much as possible and that people should be given the opportunity to exercise some autonomy. According to Kielhofner (2002) the goal of occupational therapy intervention should be to facilitate change through providing the opportunity for the person experiencing dysfunction to engage in specific occupations.

From the findings it is evident that being provided with the opportunity to engage in occupations that hold positive meaning to them was beneficial to the participants' ability to adapt to their environment. Occupational therapy intervention could play a positive role in addressing poor treatment outcomes of TB patients by helping them cope better with the effects of institutionalisation.

This could be achieved by addressing occupational risk factors by implementing occupational enrichment programmed that facilitate occupational engagement. Occupational enrichment will be beneficial to the patients at the hospital, as it will provide them with opportunities for meaningful occupational engagement as well as promote the fulfilment of various occupational roles while hospitalised as well as encouraging healthy routines.

Moreover, occupational therapy can play a key role in strengthening these support systems in the community while the patient is still in hospital. This will ensure successful reintegration into the community with the necessary support systems in place which is essential to ensure treatment adherence in TB patients. The aim of occupational therapy intervention should be to facilitate agency in TB patients and allow them the take responsibility and control over their health and well- being thereby encouraging more effective reintegration into the community. This can be achieved through enhancing their ability to care for their needs and the needs of others and to make informed decisions about their health and well- being as well as strengthening support systems of the patient. . In addition, intervention should facilitate the patients' goal setting process thereby allowing them to consider which aspects in their lives are most important to them that need to be addressed for successful reintegration to society and improved treatment outcomes.

Occupational therapy intervention could therefore play an integral role in the successful adaptation to the hospital environment through facilitating occupational engagement that is in line with patients' occupational roles both inside and outside the hospital. This can be achieved by simulating as normal lives as possible for

patients while in hospital which will have a positive impact on their sense of self as well as their motivation to plan their futures.

## **5.6 THE PARTICIPANTS' EXPERIENCE OF OCCUPATIONAL ADAPTATION WHILE UNDERGOING LONG-TERM HOSPITALISATION**

The purpose of this study was to gain an understanding of the phenomenon of occupational adaptation through the experiences of occupational adaptation by adults diagnosed with MDR TB who undergo long-term hospitalization. In their theory of occupational adaptation, Schkade and Schultz (1992) describe occupational adaptation as an internal process in which people's desire to engage in meaningful occupation is integrated with their attempt to achieve competence in their desired occupations. The occupational adaptation model (Schkade & Schultz, 1992) is comprised of four main constructs namely occupation (active engagement in meaningful activities that result in an end product), adaptive capacity (awareness of the need for adaptation to achieve competence), relative mastery (ability to respond to occupational demands through the use of time, energy and available resources) and the occupational adaptation process.

Occupational adaptation refers to adaptations in doing that people require to enable them to respond to internal (personal) and/or external (environmental) demands in order to perform occupations successfully. It is an interactive process that draws on people's occupational identity i.e. their sense of self as occupational beings and occupational competence i.e. how well they remain true to their

values, maintain their roles, and pursue their goals. The three main components influencing the occupational adaptation process are the person, the occupational environment and the interaction between the person and the environment. Within the context of this study, person refers to the adult with MDR TB who undergo long-term hospitalization, occupation refers to those occupations they engaged in while hospitalized and environment refers to the hospital where they underwent long-term hospitalisation.

Schkade and Schultz (1992) state that occupational challenges stimulate change or adaptation in attitudes or actions that leads to competence. They emphasize that the occupational adaptation process can be disrupted by impairment or stressful events. The findings of this study highlighted that the effects of long-term hospitalisation disrupted the adaptation process of the study participants. These effects that include occupational risk factors and institutionalisation, manifested in a lack of opportunities for meaningful engagement in the activities presented at the hospital as well as an inability to fulfil occupational roles. The findings of the study showed that the participants had a desire to achieve competence but that the constraints that they experienced prevented them from achieving this. As a result, the participants mainly focused on being discharged from the hospital as opposed to setting goals and developing strategies to meet their treatment outcomes.

The findings of the study demonstrated that the participants showed some adaptive capacity and progression along the occupational adaptation process while in hospital. With regards to this the findings illustrated how occupational adaptation was facilitated through the participants' active engagement in

occupation and through their adaption to certain environmental and occupational demands. The findings also highlighted examples of personal values associated with the degree of occupational adaptation that the participants achieved namely having their basic needs met, retaining choice and control and maintaining spirituality and social relationships. Occupations that gave participants opportunities to satisfy their personal values stood out in the findings such as supporting other people, upholding their daily routines and actively participating in the occupations that held meaning and purpose such as beading and washing cars to generate an income.

In this study occupational adaptation required active engagement on the part of the participants as well as a reliance on other persons for support. The occupational adaptation process was facilitated by the participants' setting goals which motivated them to overcome some constraints to their occupational performance. Their utilization of their personal resources such as their skills, spirituality and positive thinking, instilled a sense of belief in the participants that they could overcome the constraints they experienced and meet their goals. The participants' attempts at achieving adaptive capacity was evident in the findings in that it showed how they resorted to personal resources, developed and relied on their own support systems and actively pursued meaning and purpose in their occupational performance. The findings indicated that the participants' adaptations mainly related to personal and occupational factors in terms of them maintaining their personal values and occupational interests. The findings further showed that the participants were resistant to adapt to the external environment of the hospital as it did not meet their needs and that the environment was not

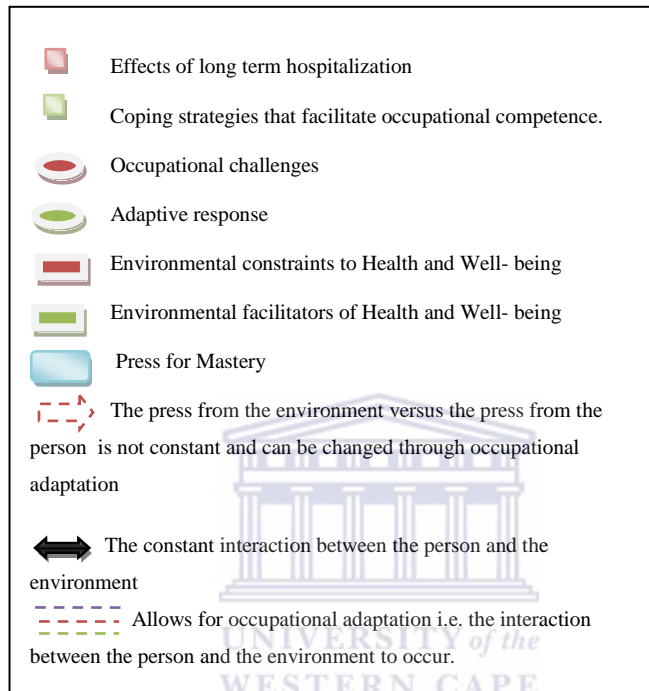
adapted to support the participants' to meet those needs. It can therefore not be concluded that the degree of occupational adaptation that the participants achieved resulted in relative mastery of their occupational performance.

According to Schkade and Schultz (1992) the facilitation of occupational adaptation should be client- centred and the role of the occupational therapist is to assist the person to identify performance problems and to initiate plans towards meeting his/her goals. The findings of this study showed that the participants felt that the hospital programme did not cater for all of their needs. Schkade and Schultz argue that a person will be more motivated to adapt when the occupations that the person engage in is personally meaningful, when the demands of the occupation can be managed, and when the adaptive nature of the person and the outside press from the environment equals the person's capacity to adapt and successfully perform. The findings of this study however showed that the press from the hospital environment was greater than the patients' adaptive capacity; therefore the participants were unable to perform successfully.

The participants' inability to perform was closely linked to their lack of autonomy and was a recurring theme throughout the findings. There was however one participant who showed relative mastery as the environment provided her the opportunity to master the skill of beading in an effort to pursue her goal of income generation. Besides practicing and developing her beading skills there were however no opportunities available for her to acquire skills around developing and managing a business. Opportunities like these would have been beneficial to her in terms of her overall health and wellbeing associated with her overall TB

treatment outcomes. Figure 2 is a diagrammatical representation of the occupational adaptation process as the participants experienced it.

Key to Figure 2:





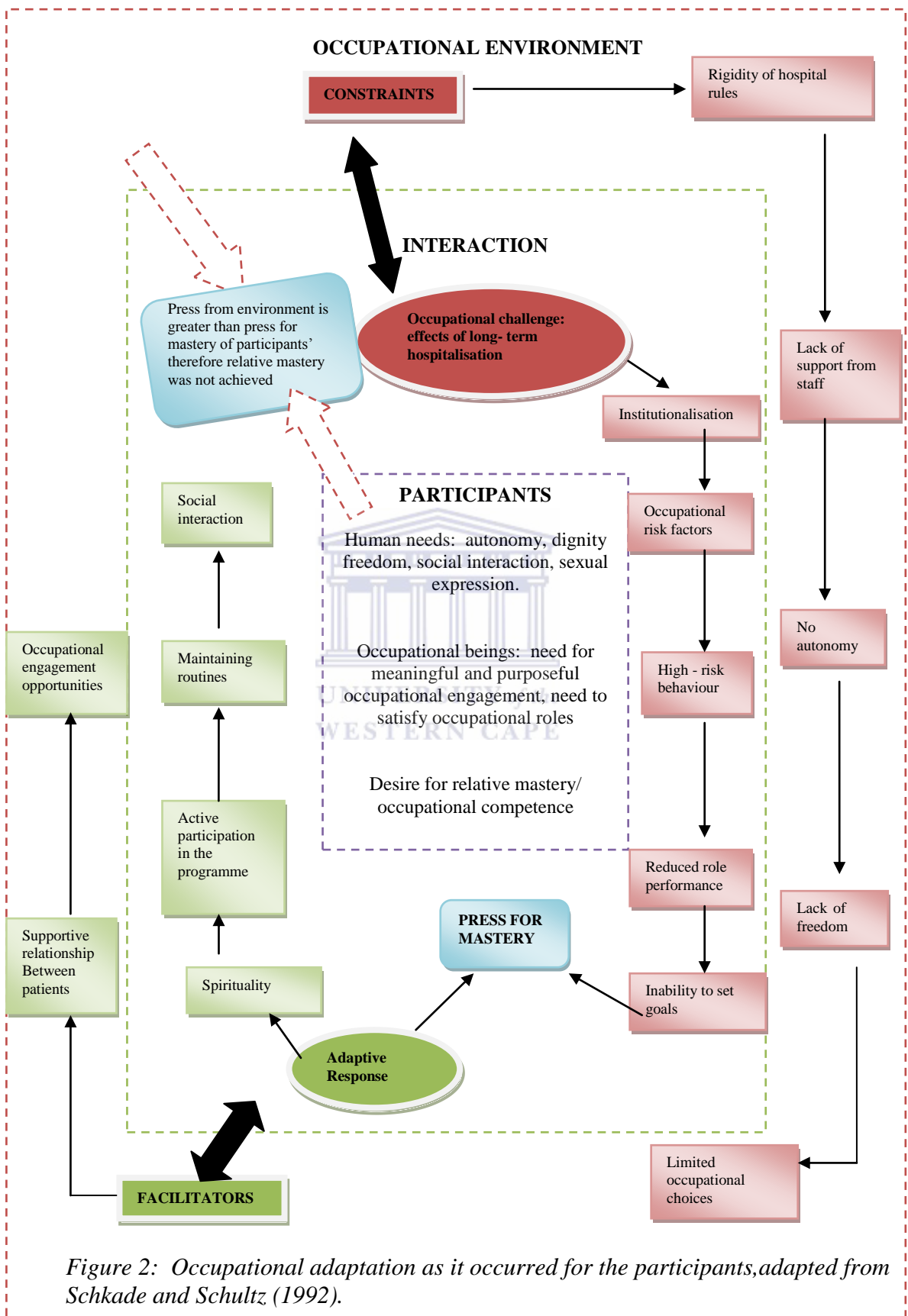


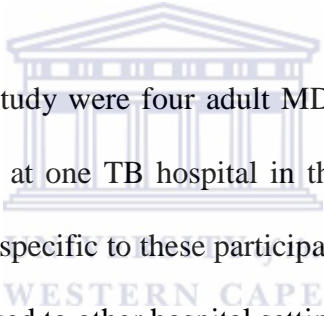
Figure 2: Occupational adaptation as it occurred for the participants, adapted from Schkade and Schultz (1992).

When looking at the findings of the study conducted by Parsons and Stanley (2008) on occupational adaptation from the perspectives of people with traumatic brain injuries, the findings revealed that meaningful occupational engagement was essential in the adaptation process of the participants. The findings of their study further highlighted the important role that environmental and social support played in the adaptation process. This is in line with the need for meaningful occupational engagement and social support that was highlighted for this study's participants.

Cognilio et.al. (2010) assert that the clubhouse model provides peer support to its members and encourages a sense of social inclusion and belonging, interdependency and a shared sense of accomplishment through engaging in activities together. The core principles of this model are that programme members are provided with a supportive environment where they are accepted and where there is commitment to assist them to meet their full potential; that they are regarded as adults who have something to contribute as opposed to allowing them to adopt the role of a patient; that they are encouraged to explore employment opportunities and that they are allowed to choose the activities they engage in based on their interests (Fountain House, 1999). These core principles are all issues that were raised by the participants of this study for example their need for freedom, autonomy, dignity and meaningful occupational engagement; the positive impact of peer support; their ability and/or lack of ability to respond to environmental and occupational demands, and the need to redefine their roles while in hospital.

The clubhouse model will allow patients who undergo long- term hospitalization to exercise more choice and control over their occupational engagement. Consequently, their occupational engagement will be more meaningful and purposeful to them; they will be using their time, energy and resources more efficiently and will be more able to set achievable goals. Accordingly, the patients will experience greater satisfaction from their occupational engagement thereby increasing their chances to obtain relative mastery and to experience occupational competence.

## **5.7 STUDY LIMITATIONS**



The participants of this study were four adult MDR TB patients who underwent long-term hospitalization at one TB hospital in the Western Cape, therefore the findings of this study are specific to these participants and to this particular setting thus it cannot be generalised to other hospital settings.

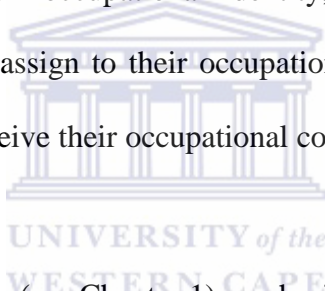
The next chapter will summarize the main conclusions drawn from the study and provide the study recommendations.

## CHAPTER 6

### CONCLUSION AND RECOMMENDATIONS

#### 6.1 INTRODUCTION

The aim of this study was to explore how adults with MDR- TB who undergo long-term hospitalisation at a hospital in the Western Cape experience occupational adaptation. The objectives of the study were to explore how the participants perceive their occupational identity, to explore the meaning and purpose the participants assign to their occupational engagement and to explore how the participants perceive their occupational competence.



The rationale of this study (see Chapter 1) emphasised the need to explore the role that occupational therapy could play in addressing poor treatment outcomes in MDR TB patients. To this end, I emphasised the importance of generating an understanding of how long- term hospitalisation influences the occupational adaptation of MDR TB patients as this understanding would in turn facilitate an understanding of their occupational needs. This understanding was regarded as necessary to develop interventions that could enhance satisfactory occupational adaptation of TB patients thereby increasing their capacity for positive treatment outcomes for TB and health and well-being. This chapter will highlight the conclusions drawn from the study in order to provide recommendations for

occupational therapy intervention in the context of the long-term hospitalization of MDR TB patients.

## **6.2 MAIN CONCLUSIONS**

Hippocrates (460 BC- 370 BC) said, “It is far more important to know what type of person has the disease than to know what type of disease the person has”. The findings of this study highlighted that the participants are people first and MDR-TB patients second. While the participants’ medical needs might have changed due to their diagnosis and while their physical environment changed due to their hospitalisation, their basic needs and who they are as individuals have not. They are human beings, family members, parents and workers, who have occupational needs as well as interests and skills. The findings revealed that not having their needs met while in hospital had an impact on how the participants’ viewed themselves and on how they perceived their health and well-being.

The study findings also highlighted that the participants viewed themselves as occupational beings and that they valued the role that occupational engagement played in facilitating their occupational competence and ultimately their ability to adapt to long- term hospitalisation. The environmental demands and constraints that they experienced however infringed their engagement in meaningful occupation and hampered their ability to achieve occupational competence. As a result they experienced occupational risk factors and institutionalisation.

The findings highlighted the role that spirituality, active involvement in the

hospital programme and social connections played in the meaning and purpose that the participants' attached to their occupational engagement. They found meaning and purpose in their occupational engagement when it enhanced their self-esteem and provided them with a sense of enjoyment.

The findings of this study further indicated that in order to establish a therapeutic milieu within the hospital and achieve better treatment outcomes for MDR TB patients, their needs have to be taken into consideration. This implies that the hospital move away from a strictly biomedical approach and adopt a more integrated approach where the patients' thoughts, feelings and needs are respected and decisions made collaboratively with them in order to achieve the best results. Occupational therapists can play a positive role in improving treatment outcomes for MDR- TB patients by addressing occupational risk factors that contribute to institutionalization and by facilitating occupational adaptation through occupational enrichment programmes and making use of psychosocial rehabilitation principles.

### 6.3 RECOMMENDATIONS

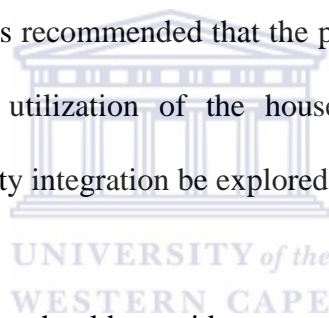
Based on the findings of this study the following recommendations are made in terms of:

#### **6.3.1. The hospital programme**

It is recommended that the clubhouse model of psychosocial rehabilitation be implemented to facilitate occupational adaptation at the hospital. Moreover, it is

recommended that the intervention programme at this hospital address the patients' need for autonomy and support. It should provide opportunities for meaningful occupational engagement and include activities over weekends as well as regular family events to encourage family support.

It is recommended that the hospital programme focus on strengthening support systems between the patients and their families by including regular family days where the patients' families have the opportunity to spend time with them. In addition family days should be utilised by team members to include the family in setting goals with the patient and to discuss the patient's progress or any questions the family may have. It is recommended that the purpose of the patient houses be reviewed and that the utilization of the houses as step down facilities in preparation for community integration be explored.

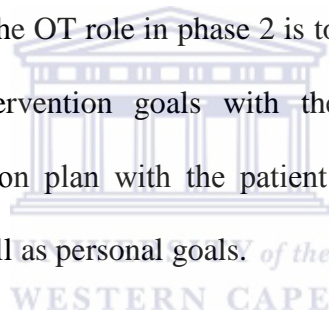


The hospital programme should provide opportunities for the participants to acquire new skills that would be beneficial to their adaptation process such as life skills and income generation skills. In light of the fact that spirituality holds positive meaning and purpose for the participants of this study, it is recommended that the programme incorporate activities that promote spirituality. The programme should also allow for flexibility so that participants do not feel that they are forced to participate in it.

Therefore, it is recommended that the programme encompass four phases that commence as soon as the patient is admitted into the hospital and continue until he/ she is discharged.

Phase 1 is the assessment phase which should take place within the first two weeks of admission to the hospital. It is required for each team member to do an assessment based on their scope of practice. The OT role during this phase is to conduct an interview with the patient to uncover background information; assess the patient's interests and level of skills and build a rapport with him/ her.

Phase 2 is the orientation and preparation phase where each team member orientate the patient to specific services available within their scope of practice. The duration of phase 2 would be 2 weeks to allow the patient to adjust to the hospital environment. The OT role in phase 2 is to orientate the patient to the OT programme, to set intervention goals with the patient and to develop an individualised intervention plan with the patient based on the patient's needs, interests and skills as well as personal goals.



Phase 3 is the intervention phase. Certain interventions such as the taking of medication and other intervention specific to the biological progression of the disease and physical well- being e.g. chest physiotherapy, mobilisation and endurance training should be compulsory as it is directly linked to the progression of the disease. All psychosocial aspects of the programme aimed at deinstitutionalisation should however be voluntary. The duration of Phase 3 should be ongoing depending on the length. The OT role during this phase is to simulate as normal an environment as possible by providing opportunity for meaningful occupational engagement, utilising aspects of the clubhouse model and implementing psychosocial rehabilitation principles.



Phase 4 is the final phase of hospitalisation and should prepare the patient for discharge with the aim of reintegration into the community. The OT focus is on specific prevocational skills in line with the patient's goals, family sessions and networking with support systems in the community. The patient houses must be used more effectively during this phase to prepare the patients for community living. This must be done by providing them with additional responsibilities; more privacy, a more 'homely' environment as well as more freedom of movement outside of the hospital in order to prepare them for reintegration into the community. Depending on their prognosis, it would also be necessary to prepare patients to be discharged without medication and/or address issues around death and dying with the patients where appropriate during this phase. Each phase of the programme must be re-evaluated on a regular basis and the overall vision and mission of the team specified.

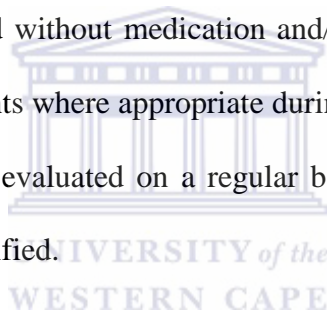
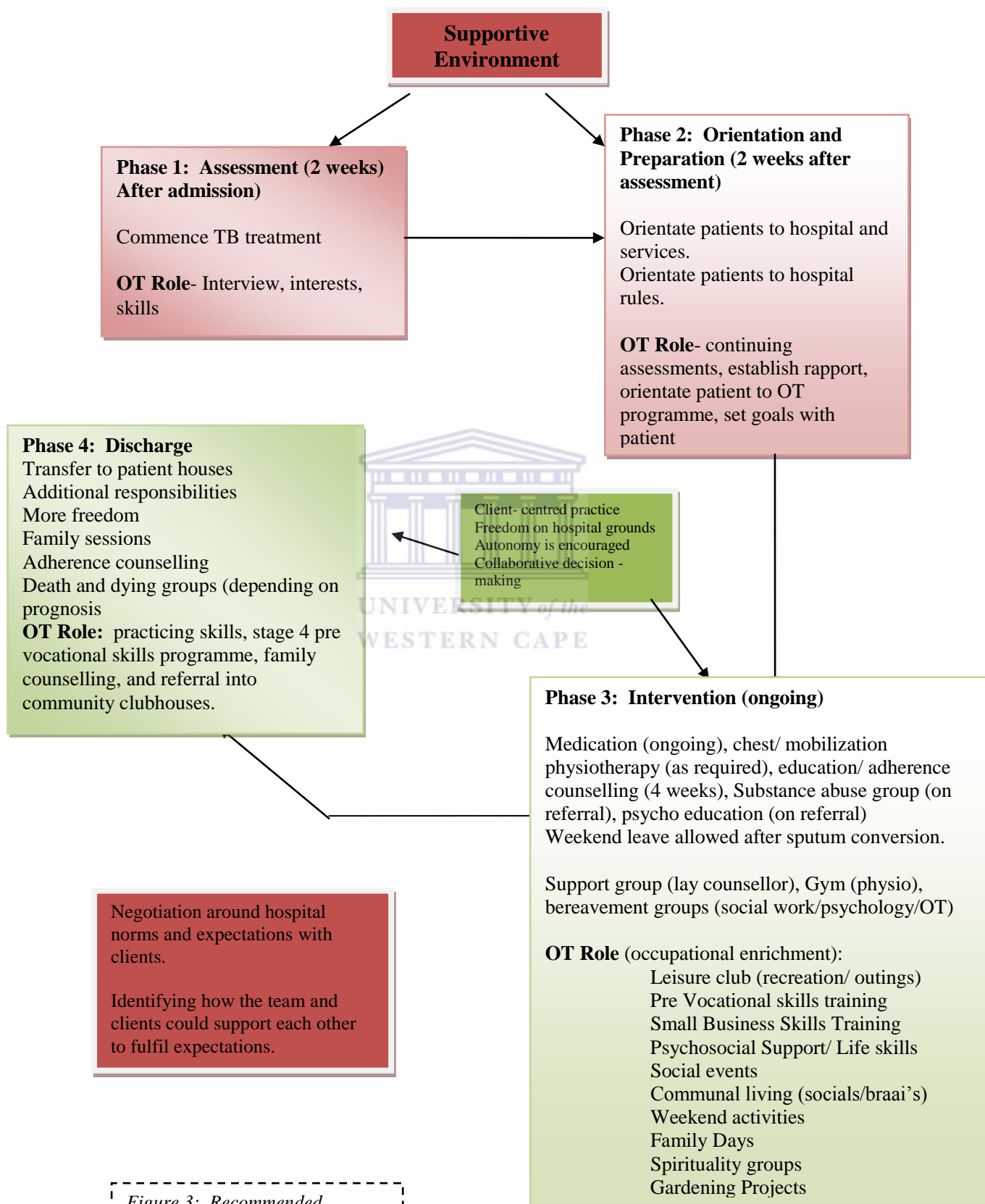
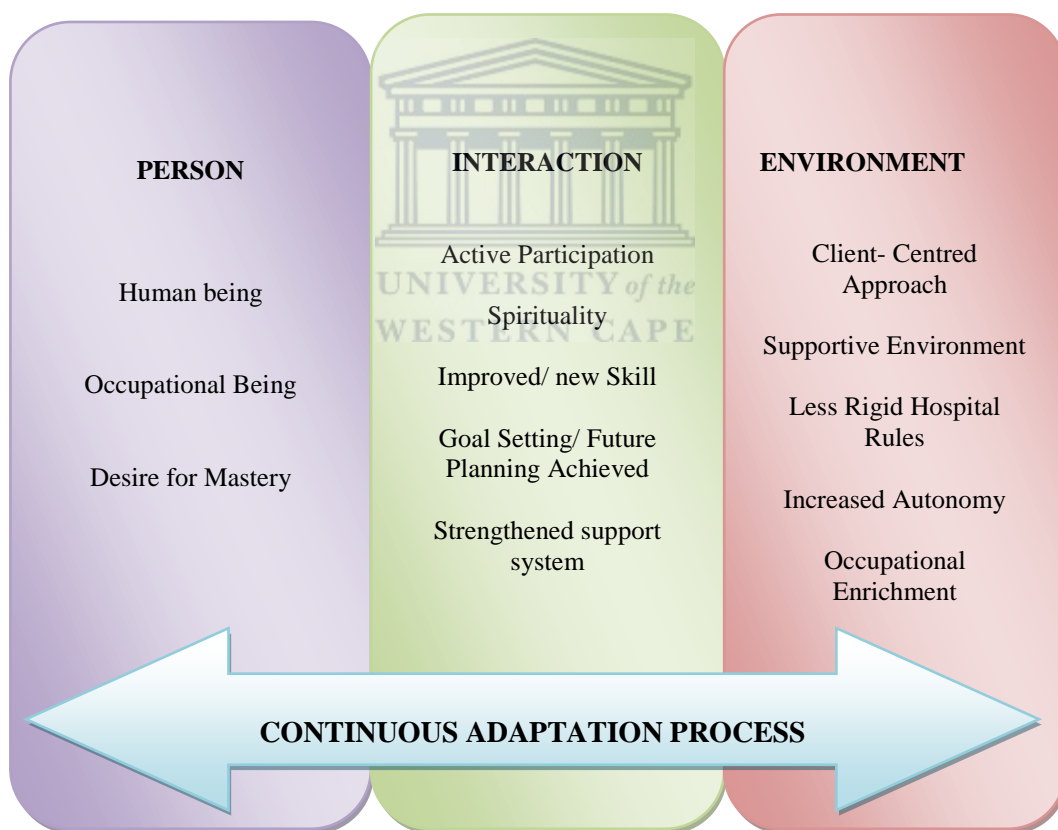


Figure 3 is a diagrammatical representation of the recommended intervention programme that includes specific activities for each phase while keeping in mind aspects of the clubhouse model as well as psychosocial rehabilitation principles.



*Figure 3: Recommended intervention programme*


It is envisaged that the implementation of this integrative intervention plan address the needs of the participants as well as the general effects of institutionalisation. The programme will result in better interconnectedness between the patients, the hospital environment and the interaction between them thereby enhancing their occupational adaptation and facilitating relative mastery. Figure 4 illustrates the continuous occupational adaptation process that I envisage to be the outcome of the integrative intervention strategies that are recommended for this hospital.



*Figure 4: Envisaged Occupational Adaptation Process*

### **6.3.2. The Occupational Therapy Programme**

It is recommended that the OT programme at the hospital is transformed from a generic programme for all patients to a client- centred programme that includes all aspects of occupation that are meaningful and purposeful to them such as spirituality, socialization, work, caring for others and sexual expression. This will allow programme activities to meet the needs, interests and skills of the patients. OT group sessions (life- skills, pre- vocational skills, psychosocial support group, socials, and events) should be voluntary thereby allowing the patients to have more autonomy over their occupational engagement



Considering that work is an important aspect of the clubhouse model, it is further recommended that pre- vocational skills training be implemented that cater for the patients various level of skill and occupational needs. Consideration should be given to the inclusion of administration tasks, electrical work, cleaning, cooking, and gardening activities in the programme. The pre- vocational activities should be graded according to the level of skill required i.e. Level 1- basic arts and crafts and creative activities; Level 2- More complex work such as carwashes and gardening; Level 3- Jobs at the hospital e.g. admin, carpentry, cleaning, laundry, ironing, contract work, skills training projects; Level 4- acquire outside projects in preparation for discharge. This level of skills training should be based on the patients' goals and should include CV writing, simulated interviews, small business skills training and general vocational skills that they could utilise upon reintegration into the community. The patients should be allowed to choose which

level of activities they participate in based on their level of skill and interests as determined in phase 1 and 2 of the recommended hospital programme.

In addition to pre- vocational skills training, it is additionally recommended that the OT programme incorporate aspects of spirituality for example group discussions around topics of spirituality, guest speakers and the use of narratives or story- telling to allow the patients to express their spirituality.

It is further recommended that OT intervention simulate ‘normal’ community living as far as possible and include a leisure club where patients are given more responsibilities in the planning of their socials events as opposed to having staff planning all events for them. This will allow them to be more actively involved in collaborative decision-making between staff and patients. Such activities will also contribute to a sense of community thereby furthering support systems amongst each other. It is also recommended that weekend activities be included in the programme to encourage constructive and meaningful use of time over weekends.

### 6.2.3 The Department of Health

It is recommended that the Department of Health establish policies around the incorporation of psychosocial rehabilitation principles in the management of MDR- TB patients as well as protocols around the establishment of community based support programmes that could apply the clubhouse model principles with the aim of going beyond adherence counselling and DOTS to also offer additional support in line with client- centred goals. Support mechanisms should be put in

place within communities to ease the transition from institution to home for example, providing quality services and support in the community from professionals as well as strengthening family systems through family counselling sessions.

#### 6.2.4 Further research

Further research should be conducted to explore the efficacy of an integrated treatment approach in the management of MDR- TB patients who undergo long-term hospitalisation. Research exploring the impact of strengthened community support structures on treatment outcomes in drug resistant TB will also be beneficial in combating the progression of the disease. Research on the role of specific occupational therapy interventions i.e. incorporating spirituality in OT programmes and the effect it has on TB treatment outcomes would further generate understandings around the role that OT could play in the TB context.

## REFERENCES

Ahern, K. (1999). Ten Tips for Reflexive Bracketing. *Qualitative Health Research*, 9(3): 407- 411.

Ashbury, J. (1995). Overview of Focus Group Research. *Qualitative Health Research*. Vol. 5(4). Sage, London: 414- 420.

Atkinson, P. & Coffey, A. (1997). Analysing Documentary realities. In Silverman, D. (Ed.). *Research Theory, Method and Practice*. Sage, London: 45- 62.

Babbie, E. & Mouton, J. (2001). Qualitative Studies (Chapter 10, 269- 312). In E. Babbie, and J. Mouton (Eds.). *The Practice of Social Research*. Oxford University Press: Cape Town, South Africa.



Babbie, E. & Mouton, J. (2001). Evaluation Research (Chapter 12, 333- 372). In E. Babbie, and J. Mouton (Eds.). *The Practice of Social Research*. Oxford University Press: Cape Town, South Africa.

Barbour, R.S. & Kitzinger, J., (1999). *Developing Focus Group Research. Politics, Theory and Practice*. SAGE Publications, London, UK.

Barros, D.D., Ghirardi, M.I. & Lopes, E. (2005). Social Occupational therapy. A Socio- Historical Perspective (Chapter 11, 140- 151). In F. Kronenberg,, S.S.

Algado, & N. Pollard (Eds.). *Occupational Therapy without Borders: Learning from the Spirit of Survivors*. Churchill Livingstone. London, UK.

Boyce, C. & Neale, P. (2006). *Conducting In- Depth Interviews: A guide for designing and guiding in- depth interviews for evaluation input*. Pathfinder International, USA.

Braun, V. & Clarke, V., (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, 3: 77- 101.

Bynon, S., Wilding, C. & Eyres, L. (2007). An innovative occupation- focused service to minimize deconditioning in hospital: Challenges and solutions. *Australian Occupational Therapy Journal*, 54: 224- 227.

Cognilio, F.D., Hancock, N. & Ellis, L.A. (2010). Peer Support within Clubhouse: A Grounded Theory Study. *Community Mental Health Journal*, [www.springerlink.com/index/DQ061257U8723777.pdf](http://www.springerlink.com/index/DQ061257U8723777.pdf). Accessed 14 September 2011.

Corti, L. (1993). Using Diaries in Social Research. *Social Research Update*, Surrey University, <http://sru.soc.surrey.ac.uk/SRU2.html>. Accessed 15 May 2010.

Dein, S. (2006). Religion, spirituality and depression: implications for treatment and research. *Primary Care and Community Psychiatry*, 11(2): 57-72.



Department of Health, South Africa (2004). *The South African National Tuberculosis Control Programme: Practical Guidelines*. Department of Health, South Africa.

Department of Health, South Africa (2008). *Management of Drug-resistant Tuberculosis: Draft Policy Guidelines*. Department of Health, South Africa.

Department of Health, South Africa (2009). *National Tuberculosis Management Guidelines*. Department of Health, South Africa.

Doble, S.E. & Santha, J.C. (2008). Occupational well-being: Rethinking occupational therapy outcomes. *Canadian Journal of Occupational Therapy*, 75(3): 184- 190.



Duncan, M. (2004). Occupation in the Criminal Justice System (Chapter 9, 129-142). In R, Watson, L, Swartz (Eds.). *Transformation through Occupation*. Whurr Publishers Ltd. London, UK.

Duncan, M. (2004). Promoting mental health through occupation (Chapter 14, 198- 219). In R, Watson, L, Swartz (Eds.). *Transformation through Occupation*. Whurr Publishers Ltd. London, UK.

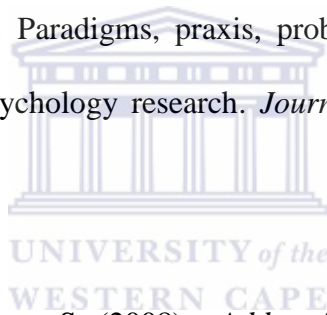
Eagle, G., Hayes, G. & Sibanda, T., (1999). Standpoint Methodologies: Marxist, feminist and black scholarship perspectives (Chapter 23, 438- 461). In M. Terre

Blanche and K. Durrheim (Eds.). *Research in Practice: Applied Methods for the Social Sciences*. University of Cape Town Press: Cape Town, South Africa.

Eichelberger, R.T. (1989). *Disciplined Inquiry: Understanding and doing Educational Research*. Longman, New York.

Farnworth, L. & Muñoz, J.P. (2009). An occupational and rehabilitation perspective for institutional practice. *Psychiatric Rehabilitation Journal*, 32(3): 578-584.

Fassinger, R. E. (2005). Paradigms, praxis, problems, and promise: Grounded theory in counselling psychology research. *Journal of Counselling Psychology*, 52: 156-166.



Feeney, L. & Toth- Cohen, S. (2008). *Addressing Spirituality for clients with physical disabilities*. Department of Occupational Therapy faculty papers. Paper 11. <http://jdc.jefferson.edu/otfp/11>. Accessed on 29 August 2011.

Finlay, L. (2009). Debating Phenomenological Research Methods. *Phenomenology and Practice*, 3(1): 6- 25.

Fountain House. (1999). The wellspring of the Clubhouse Model for social and vocational adjustment of persons with serious mental illness. *Psychiatric Services*, 50, 1472-1476.

George, L.K., Larson, D.B., Koenig, H.G. & McCullough, M.E. (2000). Spirituality and Health: what we know and what we need to know. *Journal of Social and Clinical Psychology*, 19(1): 102- 116.

Grimwood, A., Almeleh. C., Hausler, H. & Hassan, F. (2006). HIV and Tuberculosis Update. *South African Health Review*. Health Systems Trust: 77-95  
[http://www.hst.org.za/uploads/files/chap5\\_06.pdf](http://www.hst.org.za/uploads/files/chap5_06.pdf). Accessed 8 March 2007.

Guion, L.A., Diehl, D.C. & McDonald, D. (2002). *Triangulation: Establishing the Validity of Qualitative Studies*. <http://edis.ifas.ufl.edu/fy394>. Accessed on 11 September 2011.

Hagedorn, R. (2001). *Foundations for Practice in Occupational Therapy*, 3<sup>rd</sup> edition. Churchill Livingstone. London, UK.



Hammel, K. W. (2004). Dimensions of meaning in the occupations of daily life. *Canadian Journal of Occupational Therapy*, 71(5): 296- 305.

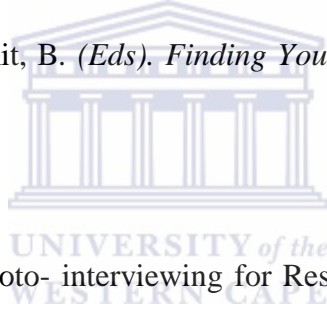
Hammel, K. W. (2009a). Sacred Texts: A Sceptical exploration of the assumptions underpinning theories of occupation. *Canadian Journal of Occupational Therapy*, 76(1): 6- 13.

Hammel, K. W. (2009b). Self- care, productivity and leisure, or dimensions of occupational experience? Rethinking occupational “categories”. *Canadian Journal of Occupational Therapy*, 76(2): 107- 114.

Haney, C. (2002). 'The Psychological Impact of Incarceration: Implications for Post- Prison Adjustment', paper presented at the From Prison to Home Conference, University of California, Santa Cruz, January 30- 31.

Harper, D. (2002). Talking about Pictures: A Case for Photo Elicitation. *Visual Studies*, 17(1): 13- 26.

Henning, E., van Rensburg & W., Smit, B. (2004). Theoretical frameworks, conceptual frameworks and literature reviews (Chapter 2, 12- 27). In Henning, E., van Rensburg, W. & Smit, B. (Eds). *Finding Your Way in Qualitative Research*. Van Schaik, Pretoria



Hurworth, R. (2003). Photo- interviewing for Research. *Social Research Update* (40). University of Surrey, Guilford, UK.

Jacelon, C.S. (2005). Participant Diaries as a Source of Data with Older Adults. *Qualitative Health Research*, 15: 991- 997.

Kielhofner, G. (1983). *Health through Occupation: Theory and practice in Occupational Therapy*. Philadelphia: F.A. Davis.

Kielhofner, G. (ed.) (1995). *A Model of Human Occupation: Theory and Application*. 2<sup>nd</sup> edition. Williams & Wilkins, Baltimore, MD.

Kielhofner, G. (ed.) (2002). *A Model of Human Occupation: Theory and Application*. 3<sup>rd</sup> edition. Lipincott Williams & Wilkins, Baltimore, MD.

Kielhofner, G. (2007). *A Model of Human Occupation: Theory and Application*. 4<sup>th</sup> edition. Lipincott Williams & Wilkins.

Kirsh, B. (1996). A narrative approach to addressing spirituality in occupational therapy: Exploring personal meaning and purpose. *Canadian Journal of Occupational therapy*, 63(1): 55- 61.

Kitzinger, J. (1995). Qualitative Reasearch: Introducing Focus Groups. *British Medical Journal*, 311: 200- 302.

Klinger, L. (2005). Occupational Adaptation: Perspectives of People with Traumatic Brain Injury. *Journal of Occupational Science*, 12: 9- 16.

Law, M., Steinwender, S. & Leclair, L. (1998). Occupation, Health and Well-Being. *Canadian Journal of Occupational Therapy*, 65(2): 81- 91.

Lester, S. (1999). *An Introduction to Phenomenological Research*. Stan Lester Developments, Taunton.

Mack, N., Woodsong, C., Macqueen, K.M., Guest, G. & Namey, E. (2005). *Qualitative Research Methods: A Data Collector's Field Guide*. Family Health International, North Carolina, USA.

Massey, C. & Lewis, K. (2004). *Help or Hindrance? Participant diaries as a qualitative data collection tool*. [http://sme-centre.massey.ac.nz/files/Lewis-Help\\_or\\_hindrance.pdf](http://sme-centre.massey.ac.nz/files/Lewis-Help_or_hindrance.pdf). Accessed on 14 September 2011.

Maslow, A.H. (1943). A Theory of Human Motivation. *Psychological Review*, 50: 370- 396.

Matebesi, Z. & Booyesen, F. (2004). Treatment adherence among Tuberculosis Patients. *Acta Academica*, 36(3): 140- 171.

Max- Neef, M. (1991). *Human Scale Development: Conception, application and further reflections*. Apex Press, New York.

Medecins Sans Frontiers, South Africa (2009). *A patient- centred approach to drug resistant tuberculosis in the community: a pilot project in Khayelitsha, South Africa*. Medecins Sans Frontiers, South Africa.

Molineux, M.L. & Whiteford, G.E. (1999). Prisons: From Occupational Deprivation to Occupational Enrichment. *Journal of Occupational Science*, 6(3): 124- 130.

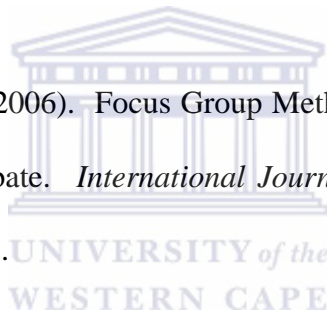
Normon, C. (2006). The Fountain House Movement, an alternative rehabilitation model for people with mental health problems, members' descriptions of what works. *Scandinavian Journal of Caring Sciences*, 20(2): 184- 192.

Nelson, D.L. (1988). Occupation: Form and Performance. *American Journal of Occupational Therapy*, 42(10): 633- 641.

Orb, A., Eisenhauer, L. & Wynaden, D. (2001). Ethics in Qualitative Research. *Journal of Nursing Scholarship*, 33(1): 93- 96.

Ospina, S. (2004). Qualitative Research (1279-1284). In G. R. Goethals, G. S. Sorenson, & J. M. Burns, *Encyclopedia of Leadership* (2004), Sage Publications, Thousand Oaks, CA.

Parker, A. & Tritter, J. (2006). Focus Group Method and Methodology: Current Practice and Recent Debate. *International Journal of Research and Method in Education*, 29(1): 23- 37.



Parsons, L. & Stanley, M. (2008). The lived experiences of occupational adaptation following brain injury for people living in rural areas. *Australian Occupational Therapy Journal*, 55(4): 231- 238.

Patton, M.Q. (1990). *Qualitative Evaluation and Research Methods*. Sage Publications, Newbury Park.

Pentland, W. & McColl, M.A. (2008). Occupational Integrity: Another perspective on “life balance”. *Canadian Journal of Occupational therapy*, 75(3): 135-138.

Portwig, G.H. & Couper, I.D. (2006). A qualitative study of the reasons why PTB patients at clinics in the Wellington area stop their treatment. *SA Family Practice: 48(9): 17.*

Robinson, N. (1999). The use of focus group methodology- with selected examples from sexual health research. *Journal of Advanced Nursing, 29(4): 905-913.*

Rowlands, B.H. (2005). Grounded in Practice: Using Interpretive Research to Build Theory. *Electronic Journal of Business Research Methodology, 3(1): 81-92.*



Rudman, D.L. (2002). Linking Occupation and Identity: Lessons learned through qualitative research. *Australian Occupational Therapy Journal, 9(1): 12- 19.*

Schkade, J.K. & Schultz, S. (1992). Occupational Adaptation: Toward a holistic approach for contemporary practice: Part 2. *American Journal of Occupational Therapy, 46(10): 917-925.*

Snowdown, K., Molden, G. & Dudley, D. (2001). Long- term illness (Chapter 19, 321-338). In J. Creek (Ed.). *Occupational Therapy and Mental Health.* Churchill Livingstone, UK.



Swartz, L. & Dick, J. (2002). Managing chronic diseases in less developed countries. *British Medical Journal*, 324: 914-915.

Terre Blanche, M. & Kelly, K. (1999). Interpretive Methods (Chapter 7, 123-146). In M. Terre Blanche and K. Durrheim(Eds.). *Research in Practice: Applied Methods for the Social Sciences*. University of Cape Town Press: Cape Town, South Africa.

Thaver, V. & Ogunbanjo, G. A. (2006). XDR TB in South Africa- What lies ahead? *SA Family Practice*, 48(10): 58- 59.

Tobin, G.A. & Begley, C.M. (2004). Methodological Rigour in a Qualitative Framework. *Journal of Advanced Nursing*, 48(4): 388- 396.

Townsend, E. (1997). Occupation: Potential for personal and social transformation. *Journal of Occupational Science, Australia*, 4(1): 18- 26.

Unruh, A. M. (1997). Spirituality and Occupation: Garden musings and the Himalayan Blue Poppy. *Canadian Journal of Occupational Therapy*, 64: 156-160.

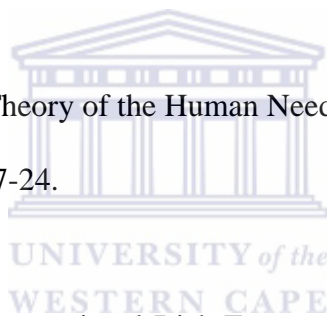
Walliman, N. (2006). *Social Research Methods*. Sage Publications, London, UK.

Weskamp, K. & Ramugondo, E.L. (2004). Taking account of spirituality (Chapter 11, 153- 167). In R, Watson, L, Swartz (Eds.). *Transformation through Occupation*. Whurr Publishers Ltd. London, UK.

Whiteford, G. (1997). Occupational Deprivation and Incarceration. *Journal of Occupational Science*, 4(3): 126- 130.

Whiteford, G.E. (2005). Understanding the Occupational Deprivation of Refugees: A Case Study from Kosovo. *Canadian Journal of Occupational Therapy*, 72(2): 78- 88.

Wilcock, A. (1993). A Theory of the Human Need for Occupation. *Occupational Science Journal*, 1(1): 17-24.



Wilcock, A.A. (1998) Occupational Risk Factors (Chapter 6, 131- 162). In A.A. Wilcock (Ed.). *An Occupational Perspective of Health*, Slack, Thorofare, NJ.

Wilcock, A.A. (1999). 'Reflections on doing, being and becoming'. *Australian Occupational Therapy Journal*, 46: 1-11.

Wilcock, A.A. ( 2006). *An Occupational Perspective of Health*, Slack, Thorofare, NJ.

Wilcock, A.A. & Townsend, E. (2004). Occupational justice and client-centred practice: A dialogue in progress. *Canadian Journal of Occupational Therapy*, 17(2): 75- 87.

Wilding, C. (2007). Spirituality as Sustenance for Mental Health and Meaningful Doing: A case illustration. *Medical Journal of Australia*, 186(10): 67-69.

World Federation of Occupational Therapists (2004). *Definition*. <http://medind.nic.in/iba/t05/i2/ibat05i2p47.pdf>. Accessed 22 March 2009.

World Health Organization (1948). *Definition of Health*. <http://www.who.int/suggestions/faq/en/index.html>. Accessed 22 March 2009.

World Health Organization, (1986). *Ottawa Charter for Health Promotion*. Ottawa, Canada. World Health Organization.

World Health Organization, Geneva (2003). *WHO Guidelines for National Programmes*. World Health Organization, Geneva.

World Health Organization (2007). *WHO Global Tuberculosis Report*. [www.who.int/tb/publications/global\\_report/2007/](http://www.who.int/tb/publications/global_report/2007/). Accessed 8 March 2007.

World Health Organization (2008). *WHO Global Tuberculosis Report*. [www.who.int/tb/publications/global\\_report/2008/](http://www.who.int/tb/publications/global_report/2008/). Accessed 22 June 2010.

World Health Organization (2010). *WHO Global Tuberculosis Report*.

[www.who.int/tb/publications/global\\_report/2010/](http://www.who.int/tb/publications/global_report/2010/). Accessed 22 June 2010.



*Appendix1: Hospital Rules*

RULES OF BEHAVIOUR FOR HOSPITAL PATIENTS

Notice is hereby given that disciplinary discharge will be considered under the Occupational Health and Safety Act 85 for patients found guilty of transgression of the rules. The following rules will apply:

1. Patients will only be allowed weekend leave after 6 weeks stay in hospital. The application of this ruling will depend on the patient's condition i.e. they must be direct negative, after which you will get one weekend per month.  
Special leave will be granted in exceptional case
2. Rest periods: All patients must rest as part of their treatment 12:00 till 13:00 unless appointments have been scheduled with other departments.
3. Everybody must remain in the ward between 7:00 to 9:00 unless appointments have been scheduled with other departments. Everybody must be back in the ward by 16:30
4. No patient shall leave the ward during doctor's ward rounds except for those who have scheduled appointment with other departments.
5. Patients must take their medication at the table/bed, under the supervision of a nurse.
6. All monies or valuable articles must be handed to the Cashier on admission; after 16:00 it can be handed to the Sister-in-charge or if the patient prefers to keep it on him/herself, he/she will do so on their own risk.
7. It is ward policy that linen will only be changed once a week. In case of soiled pyjamas, exchange early in the morning.
8. In case there is any complaint, worry or problems, report it immediately to the Sister-in-charge or alternatively making use of the complaint and

compliment boxes available in wards' foyer or request to see a social worker or ward representative.

9. Weekly climate meetings will be held where patients are allowed to raise any complaints, which will then be reported to management.
10. A patient forum is held every second month. It is compulsory for the patient representative from the ward to attend where praise and complaints can be raised with management.
11. Patients are not allowed in the front of the hospital signage areas.
12. It is each patient's responsibility to keep the bathrooms, toilets and showers tidy and neat at all times after use.
13. Patients may not gather around the rear perimeter of the hospital.
14. Patients are not allowed to wear private clothes except for private pyjamas. The rest will be locked away. Patients may wash their pyjamas with their own soap if they prefer to do so.
15. Visiting Hours:  
Saturdays/Sundays/Public holidays:  
14:00 – 16:00  
Weekdays: 14:00 – 16:00  
Night 19:00 - 20:00
16. No visitors will be allowed outside visitation times without permission from the Sister-in-charge of the ward.
17. No patient will leave the ward with visitors without the permission of the Sister-in-charge of the ward.

18. If a patient has not returned from leave on the prescribed date, the patient will be regarded as having automatically absconded against medical advice.
19. Patients may not keep perishable food in the ward and the preparation of meals in the ward is prohibited.
20. The use and dealing with alcohol, cannabis (dagga) and narcotic drugs are strictly forbidden.  
The hospital is a smoke free building; it is therefore strictly forbidden to smoke in the wards, bathrooms or any-where else in the hospital.
21. Patients should respect fellow patients, hospital staff and all hospital equipment.
22. Swearing and the use of foul language will not be permitted.
23. Spitting and littering are prohibited. Please keep hospital buildings and grounds tidy.
24. Patients in receipt of a disability Grant will forfeit their grant should they abuse alcohol or drugs.
25. PRIVATE electrical appliances may ONLY be used with written permission of the Medical Superintendent after testing by technical staff. Private TV's and DVD/CD players will only be allowed on condition the patients make use of earphones.
26. Television: Monday – Thursday: can watch until 22:00  
Weekends: can watch until 24:00
27. No loud music may be played in the wards.
28. Patients or visitors may not sit or lie on other patient's or empty beds.
29. Lights will be switched off at 22:00 weekdays  
24:00 weekends

30. Patients may attend church services between 10:00 en 11:00 in the wards.
31. Bread and tea will be served between 20:00 – 22:00
32. It is compulsory for mobile patients to attend all scheduled appointments and group sessions. Scheduled times will be communicated.
33. It is compulsory for all patients to wear a mask when attending scheduled appointments at other departments.
34. Workshop/information sessions on alcohol and narcotics and other related topics by the hospital staff are compulsory to attend as it forms part of the in-hospital treatment.
35. Excessive clothing should be sent home.
36. Patients are not allowed to trade on hospital premises.
37. Patients are not allowed to engage in sexual activity on hospital premises.
38. Referrals to social workers can go via Ward Staff.

I understand the rules and promise to abide by it.

NAME OF PATIENT: .....

SIGNATURE: .....

WITNESS: .....

PATIENT COMMITTEE.....

DR.  
SEN. MEDICAL SUPERINTENDENT

Date

Failure to adhere to hospital rules will have will result in punitive measures being implemented according to merit



Appendix 2: Ward Programme

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
6h00-7h00	Rise and Shine Bathing/ Showering/ Quiet time	Rise and Shine Bathing/ Showering/ Quiet time	Rise and Shine Bathing/ Showering/ Quiet time	Rise and Shine Bathing/ Showering/ Quiet time	Rise and Shine Bathing/ Showering/ Quiet time	Rise and Shine Bathing/ Showering/ Quiet time	Rise and Shine Bathing/ Showering/ Quiet time
7h00-8h00	Medication/ Sputums	Medication/ Sputums	Medication/ Sputums	Medication/ Sputums	Medication/ Sputums	Medication	Medication
8h00-9h00	Breakfast/ Sputums	Breakfast/ Sputums	Breakfast/ Sputums	Breakfast/ Sputums	Breakfast/ Sputums	Breakfast/	Breakfast/
9h00-10h00	OTG1+G3+ G4 Skills Training Candlemaking/ Leatherwork/ Hangerman	Physio Walk About/exercise Group	OTG2+G3+ G4 Skills Training Candlemaking/ Leatherwork/ Hangerman	ID Clinic Support Group	Climate Meeting/ Walk About	Recreation	Recreation
10h10-11h10	OTG1 1+G3+ G4 Skills Training  Candlemaking/ Leatherwork/ Hangerman  G2- OT  Life Skills	Social Work  Disability Grants	OT G2+G3+ G4 Skills Training Candlemaking/ Leatherwork/ Hangerman  G1- OT Life Skills	Social Work  Individual Consultations	Free Time	Recreation	Recreation
11h30-13h00	L	U	N	C	H		
13h00-13h45		G1- G4 Physio -Open Gym	OT Interviews  OT Stress Management	G1- G4 Physio – Open Gym	OT Social	Visitors	Visitors
14h00-14h45	G1- OT Motivational Group	Dietician Appointments will be made via the sister in charge  TB Counsellors Education	G2- OT Motio Stress Management (open group)	Audiology: appointments will be made via the sister in charge	OT Social	Recreation	Recreation
15h00-16h30	Recreation	Recreation	Recreation	Recreation	Recreation	Recreation	Recreation
16h30-17h00	S	U	P	P	E	R	39

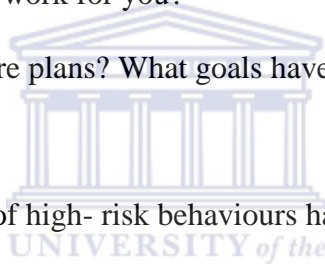
*Appendix 3: Initial Semi- structured Interview Guide*

1. What are some of the activities you enjoy doing (general)?
2. How has this changed since being admitted to hospital?
3. What are your current roles and do you feel that you are able to fulfil them effectively?
4. What activities do you actively participate in now while in hospital?
5. How much do you enjoy the activities you do at the hospital?
6. What are your reasons for your enjoyment of these activities?
7. What are some of the things you would like to do but are unable to do at the moment?



*Appendix 4: Follow- up Semi- structured Interview Guide*

1. What specific needs do you have and what are your feelings regarding your needs being met while in hospital?
2. What are your experiences around having a support system?
3. How and with what does your spirituality assist you?
4. Do you have opportunities to engage in meaningful occupation? If not, what opportunities would you find meaningful?
5. How does hospitalisation affect your roles e.g. wife, mother, father, breadwinner, worker?
6. How important is work for you?
7. What are your future plans? What goals have you set towards fulfilling your future plans?
8. What incidences of high- risk behaviours have you been involved in?
9. What needs to happen for you to be able to meet your goals?



*Appendix 5: Diary Guidelines*

Dear \_\_\_\_\_ (participant's name), please follow these guidelines when using your diary.

1. Make at least one diary entry every day.
2. Remember to date each entry.
3. Do not let the diary keeping influence your normal routine in any way.
4. You need to think about the following questions and then write down your responses in your diary:

- What did I do during the day?
- Why did I do it?
- When did I do it?
- How did I feel when I did what I did?
- Who was with me?
- How did this influence what I did or how I felt?

6. The above questions are just a guideline so feel free to elaborate on your thoughts, feelings and experiences.

You are welcome to talk to me if you have any questions about keeping your diary. Please return your diary to me on \_\_\_\_\_ (Day) \_\_\_\_\_ (Date). I will be in my office during \_\_\_\_\_ (time).


Thank You.

Nousheena Firfirey

*Appendix 6: Tabulated Description of Participant Observation*

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
7am-9am			Medication  Routine,  ADL's,  breakfast				
9am-12pm		Patients participating in Ward Programme i.e.. Task centred/ skills development sessions such as sewing and beadwork, others spend their time lying in bed all day. Participant 3 participates actively in this programme.				Participant 1 getting ready to go home for weekend leave, bathed and dressed early, increased motivation. This was observed with several other patients who were preparing to go home for the weekend.	
12pm-2pm	Lunchtime routine, Laundry, relaxing and socialising.			Lunchtime routine  Patients living in the 'house' have to do			

	<p>Some wards are fenced off and patients are not allowed to leave so other patients interact with them through the fences.</p> <p>Some patients were lying in bed</p>			<p>their own dishes and chores, whereas patients in the ward have less responsibilities</p>		
2pm-4pm		<p>Some patients participate in Discussion groups</p>		<p>Some of the Patients lying in bed, have not yet performed ADL's yet, other patients sit outside, socialising, smoking.</p>		<p>Patients socializing (listening to music, singing and dancing together) in recreational area at OT department.</p> <p>Visiting hour- few patients' relatives come to visit them. Participant 3 is one of few patients at the hospital whose family visits regularly.</p>

4pm-6pm			<p>Pts have dinner at 4h30 pm. Thereafter, Socialising, relaxing, sitting outside, Smoking</p>				<p>After dinner, Patients sitting outside socialising, smoking, females rolling each other's hair.</p>
5pm-7pm					<p>Males- Playing pool, cards and dominoes. Participant 4 doesn't engage in the dominoes/cards with other patients. He is very isolated from the rest of the ward. Females were doing each other's hair. Participant 1 is very proud of her hairdressing skills and assists others in the wards with their hair. Preparing</p>		

					<p>for weekend leave/ Patients watching TV, patients get ready for bed. According to participants 1 and 3, after watching 7de Laan on TV there is nothing to do in the evening.</p>		
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*Appendix 7: Examples of the photographs used in the focus group*



Socialising through the fence



Substance use



Socializing with each other.



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Staying in bed



Learning how to sew



Playing pool.



Washing Dishes



Playing dominoes



Doing beadwork





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## INFORMATION SHEET

**Project Title:** “Occupational Adaptation: The experiences of adult patients with MDR- TB who undergo long- term hospitalisation”

### **What is this study about?**

My research involves looking at what your experiences will you are a patient at the hospital, the occupations you engage in and the meaning and purpose they hold for you.

### **What will I be asked to do if I agree to participate?**

If you agree to participate in the study you will firstly be issued with an A4 book and a pen, or an audio cassette recorder so that you can maintain either a written or an audio diary for a period of seven days. You will have to make a diary entry every day, focusing on what you did during the day and how it made you feel. I will collect the diary from you after the seven days has been completed. I will then read through the diary and schedule an appointment with you for an interview where I will ask you more questions relating to your experiences and feelings expressed in your diary. A focus group will also be facilitated with you and four other patients where you will get the opportunity to view ten photographs that I will take during the research period. You will get the opportunity to express your views relating to the photographs.

The interview and focus group discussion will each be approximately an hour long and will be audio taped, and the tapes will be destroyed once the study is completed.

**Would my participation in this study be kept confidential?**

All information you share will be kept confidential and you will not be identified by name in any part of the study or publication thereof. You will also be required not to discuss any information shared by other members of the group. The photographs will be used in the research report; however, no faces will be depicted in the photographs to ensure anonymity.

**What are the risks of this research?**

There are no known risks associated with participating in this research project.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help the researcher to learn more about how long term hospitalisation affects the occupations you engage in. Other people might therefore benefit from this study.

**Do I have to be in this research and may I stop at any time?**

Your participation in the study is completely voluntary and you may withdraw at any time from the study without having to provide an explanation, even after it has started. Your treatment will not be affected in any way should you decide not to participate in the study. You also have the right to access the findings of the study once the study is complete.

**What if I have any questions?**

Nousheena Firfirey of the Department of Occupational Therapy at the University of the Western Cape will conduct this research. If you have any questions about the research study itself, please contact her at any time at (021) 508- 8309 or 072 268 8589 or her supervisor Ms Lucia Hess- April at the University of the Western Cape.



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**INLIGTINS VORM**

**Studie Omskrywing:** “Occupational Adaptation: Die ondervinding van volwassene pasiente met MDR- TB wat vir n lank tydperk in die hospitaal moet bly.

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**Wat behels die studie?**

My navorsing behels die opsomming van u ondervinding teenoor die feit dat u in die hospitaal vir n lank tydperk moet bly. Ek will leer ken wat u doen terwyl u n patient by die hospitaal is en wat dit vir u beteken.

**Wat sal van my verwag word, sou ek besluit om deel te neem?**

As u toestem om in die navorsing studie deel te neem sal ek vir u n A4 boek en n pen of n audiobandopnemer gee om rede dat die studie verwag van u om n dagboek vir n tydperk van sewe dae te hou. U moet elke dag in die dagboek skryf of u kan die audiobandopnemer gebruik en n verbale dagboek hou. Die dagboek gaan oor als wat u vir daardie dag gedoen het en u gevoelens oor alles wat gebeur het. Ek sal die dagboek oor sewe dae kom haal en daar deur lees.



Daarna sal ek n afspraak met u reel vir n onderhoud en n groep sessie waar ek nog vrae sal vra. Die onderhoud en groep sessie sal u die geleentheid gee om terugvoering te gee oor u ondervindinge en emosies/gevoelens. U gaan ook die geleentheid kry om deur fotos te kyk wat ek by die hospitaal gaan neem en terugvoering gee of u met die fotos kan identifiseer of nie.

Die individuele onderhoud en groep sessies sal ongeveer een uur lank wees en sal op audioband opgeneem word, maar sal vernietig word nadat die studie voltooi is.

### **Sal my deelname tydens die studie konfidentieël wees?**

Alle inligting wat u deel, sal ten alle tye konfidentieël wees en u sal nie by naam geïdentifiseer word tydens die studie óf met publisering daarvan nie. Daar sal ook van u verwag word om géén informasie te deel met ander deelnemers in die groep nie.

### **Is daar enige risikos wat verband hou met die studie?**

Daar is geen bekende risikos gepaardgaande met die studie nie.

### **Wat is die voordele van die Studie?**

Die studie is nie so ontwerp/geskryf om persoonlike hulp aan u te verleen nie, maar die resultate kan die navorser help om meer inligting oor hoe pasiënte voel as hulle vir n lank tyd in die hospital moet bly en oor sodoende sal ander pasiënte baat vind daarby.

### **Is die studie verpligtend vir my en mag ek ter eniger tyd onttrek?**

U deelname is vrywillig en u het die reg om ter eniger tyd te onttrek sonder enige verduideliking. Sou u besluit om nie deel te neem aan die studie nie, sal u behandeling geensins geaffekteer word nie. U het ook die reg op toegang tot die studie bevindinge/resultate.

### **Wat as ek vrae het?**

Nousheena Firfirey van die Arbeidsterapie Departement, Universiteit van die Wes-Kaap, sal hierdie navorsing/studie waarneem. Sou u enige navrae het

aangaande die studie, kontak haar ter eniger tyd by die volgende kontak nommer:  
(021)508- 8309 **ó**f  
072 2688 589 **ó**f haar toesighouer, Me. Lucia Hess- April by die Universiteit van  
die Wes-Kaap.



**Appendix 5: Consent Form**



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**University of the Western Cape**

**Universiteit van Wes-Kaapland**

**CONSENT FORM**

**Project Title:** “Occupational Adaptation: The experiences of adult patients with MDR- TB who undergo long- term hospitalisation”

This study has been described to me in a language I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

**Participant’s name** :

**Participant’s signature:**

**Date** :

**Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the researcher.**

**Researcher’s Name: Nousheena Firfirey**

**Tel: (021) 508-8309**

**Cell: 072 268 8589**



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### TOESTEMMINGS VORM

**Studie Omskrywing:** “Occupational Adaptation: Die ondervinding van volwassene pasiente met MDR- TB wat vir n lank tydperk in die hospitaal moet bly.”

Die studie is aan my verduidelik in ‘n taal wat ek kan verstaan en ek gee my toestemming om vrywilliglik deel te neem. My vrae aangaande die studie is beantwoord. Ek verstaan dat my identiteit nie bekend gemaak sal word nie en dat ek die reg het om ter eniger tyd van die studie te onttrek sonder enige verduideliking en dat dit nie my behandeling negatief sal affekteer nie.

**Deelnemer se naam**

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**Deelnemer se handtekening :**

**Datum :**

**Kontak asseblief die navorser sou u enige navrae hê aangaande die studie óf probleme ondervind wat verband hou met die studie.**

**Navorser se naam : Nousheena Firfirey**

**Tel : (021) 508 8309**

**Cell: 072 2688 589**