

A qualitative process evaluation of a community-based psychosocial rehabilitation programme for service users with schizophrenia in Dr. Kenneth Kaunda district, South Africa.

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A mini-dissertation submitted in partial fulfilment of the

requirements for the degree of:

MASTER OF SOCIAL SCIENCES IN CLINICAL PSYCHOLOGY

in the

School of Applied Social Sciences, Psychology discipline

at the

University of KwaZulu-Natal, Howard College

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May 2017

Declaration

I, **Musawenkosi Sphiwe Mazibuko** declare that this research thesis titled: **A qualitative process evaluation of a community-based psychosocial rehabilitation programme for service users with schizophrenia in Dr. Kenneth Kaunda district, South Africa** is my original work except where otherwise stated. I declare that this thesis has not previously been submitted for any qualification at any other university. I have acknowledged all sources in the reference list.

Musawenkosi Sphiwe Mazibuko

May 2017

Dedication

To my mother

Cabangani Florence Radebe

Who encouraged and motivated me even in times of trials and tribulations;
who sacrificed all she had so I could acquire education.

Acknowledgements

I would like to acknowledge the following people who assisted in this dissertation:

- Thank you to the participants for courageously sharing their experiences of attending the psychosocial rehabilitation programme.
- I am grateful to my supervisor Professor Inge Petersen, for allowing me to use data from the PRIME Project, and for support and guidance from the conception of this dissertation until the end.
- Thank you to Tasneem Kathree as PRIME project coordinator for administrative and logistical support.

Table of contents

| | |
|--|-----------|
| Declaration..... | ii |
| Dedication..... | iii |
| Acknowledgements..... | iv |
| Table of contents..... | v |
| ABBREVIATIONS AND ACRONYMS..... | viii |
| CHAPTER 1: INTRODUCTION | 1 |
| 1.1 Introduction and background | 1 |
| 1.2 Statement of the problem | 6 |
| 1.3 Definition of terms..... | 8 |
| CHAPTER 2: LITERATURE REVIEW | 11 |
| 2.1 Introduction | 11 |
| 2.2 Impact of schizophrenia..... | 12 |
| 2.2.1. Impact of schizophrenia on the individual..... | 12 |
| 2.2.2. Impact of schizophrenia on the family | 13 |
| 2.2.3. Impact of schizophrenia on the society | 14 |
| 2.3 Evolution of schizophrenia treatment | 15 |
| 2.4 Moral treatment | 15 |
| 2.5 The reform of the asylum and the decline of moral therapy | 15 |
| 2.6. Deinstitutionalization..... | 18 |
| 2.7. Community/psychosocial management of schizophrenia..... | 20 |
| 2.8 Psychosocial rehabilitation in the LMIC context..... | 24 |
| 2.9. Task-sharing | 28 |
| 2.9 Psychosocial rehabilitation – the South African context | 30 |
| 2.10 Challenges with decentralization of mental health care services in South Africa | 34 |
| 2.11 Theoretical approach: Complex interventions | 35 |
| 2.12 Conclusion..... | 36 |
| CHAPTER 3: RESEARCH METHODOLOGY | 38 |
| 3.1 Objectives of the study | 38 |
| 3.2 Research questions | 38 |
| 3.3 Research design and theoretical approach..... | 38 |
| 3.4. Research site | 39 |
| 3.5 Sample and sampling method | 40 |

| | |
|---|-----------|
| 3.6 Data collection | 41 |
| 3.7 Data analysis | 41 |
| 3.8 Ethical considerations | 42 |
| CHAPTER FOUR: RESEARCH FINDINGS | 44 |
| 4.1 Introduction | 44 |
| 4.2 Change in feelings and thoughts..... | 44 |
| 4.3 Most helpful aspects of the intervention | 45 |
| 4.4 Economic improvement..... | 46 |
| 4.4.1. Generating income..... | 46 |
| 4.4.2. Budgeting..... | 47 |
| 4.5 ‘Understanding our illness’ | 47 |
| 4.6 Skills gained..... | 48 |
| 4.7 Treatment adherence | 49 |
| 4.8 Aspects of the intervention that could be improved..... | 49 |
| 4.9 Family and community..... | 50 |
| 4.10 Perceptions of patients with schizophrenia toward facilitators..... | 52 |
| 4.11 PSR as a good way to support people with schizophrenia | 53 |
| 4.12 Recommending the PSR programme..... | 53 |
| 4.13. Conclusion..... | 54 |
| CHAPTER FIVE: DISCUSSION OF RESULTS | 55 |
| 5.1. Introduction | 55 |
| 5.2. Change in feelings and thoughts..... | 56 |
| 5.3. Most helpful aspects of the intervention | 57 |
| 5.3.1. Problem solving skills and social improvement | 57 |
| 5.3.2. Economic improvement..... | 58 |
| 5.3.3. Reducing risky behaviour | 60 |
| 5.3.4. Treatment adherence | 61 |
| 5.4. Aspect of the PSR that could be improved | 62 |
| 5.5. Perception of patients with schizophrenia toward facilitators | 65 |
| 5.6. Family and community changes | 66 |
| 5.6.1. Improved understanding of schizophrenia amongst family and community members.... | 66 |
| 5.6.2. PSR programme can reduce stigma | 68 |
| 5.6.3. Roles and activities..... | 69 |
| 5.6.4. Personal hygiene | 70 |

| | |
|--|-----------|
| 5.7. PSR as a good way to supporting people with schizophrenia | 70 |
| 5.8. Conclusion..... | 71 |
| CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS | 73 |
| 6.1 Conclusion..... | 73 |
| 6.2 Limitations of the study | 75 |
| 6.3 Recommendations for future interventions | 75 |
| 6.4 Recommendations for future research..... | 76 |
| References | 77 |

ABBREVIATIONS AND ACRONYMS

| | |
|-------|--|
| ACT | Assertive Community Treatment |
| ASW | Auxiliary Social Workers |
| CBR | Community-Based Rehabilitation |
| CHCWs | Community Health Care Workers |
| CHWs | Community Health Workers |
| DoH | Department of Health |
| DKK | Dr. Kenneth Kaunda District |
| ICDM | Integrated Chronic Disease Management |
| LMICs | Low- and Middle-Income Countries |
| MHCA | The Mental Health Care Act |
| MHPF | Mental Health Policy Framework |
| MRC | Medical Research Council |
| PHC | Primary Health Care |
| PORT | Schizophrenia Patient Outcomes Research Team |
| PRIME | Programme for Improving Mental Health Care |
| PSR | Psychosocial Rehabilitation |
| SES | Socio-economic Status |

Abstract

Background: Schizophrenia is a chronic disorder accompanied by impairment in cognitive functioning. In South Africa, schizophrenia is the third leading cause of disability. Historically, patients with schizophrenia have been treated in psychiatric hospitals. Psychiatric hospitals have been criticized because of inhuman conditions and human rights abuses. Furthermore, patients become institutionalized; thus they have limited access to the outside world and undergo 'mortification of the self'. Deinstitutionalization that includes community-based mental health services emerged as an alternative to institutionalization and as a best approach for increasing accessibility to mental health services. However, deinstitutionalization in developing countries has not been accompanied by adequate community-based psychosocial rehabilitation (PSR) programmes. It appears that few studies have attempted to evaluate task-shared community-based PSR for schizophrenia that require integration of mental health services into Primary Health Care (PHC) in South Africa. In addition, South Africa is currently experiencing a shortage of mental health care professionals and a mental health treatment gap of 75%. To reduce this treatment gap, task-sharing has been recommended.

Aim: The study aimed to explore and explain the experiences of patients with schizophrenia who attended the PSR programme in Dr. Kenneth Kaunda district, North West province.

Method: This study adopted a qualitative approach. The interviews were collected through the PRIME project with the purpose of conducting process evaluation of a community-based PSR programme for service users with schizophrenia in Dr. Kenneth Kaunda district (DKK), South Africa. Data was collected using one-on-one, face-to-face, semi-structured interviews with sixteen participants who were receiving follow-up medication in Grace Mokhomo and Kanana Orkney clinics in the Matlosana subdistrict of DKK district. Thematic analysis with N-vivo software was used to analyse qualitative data.

Results: Findings from this study showed that comprehensive mental health care that includes pharmacology and community-based strategies for schizophrenia is effective in

reducing symptoms of schizophrenia and improving cognitive functioning. Furthermore, the study showed that task-shared intervention has the potential to reduce stigma surrounding mental illness, improve mental health literacy, increase treatment adherence (thus reducing the revolving door syndrome), and improve social and interpersonal skills which increase support systems for affected individuals. The PSR programme also played a vital role in reducing risky behaviour. The findings of this study show that PSR interventions facilitated by properly trained and supervised non-specialist workers are likely to be effective. Effectiveness of the PSR programme shows that South Africa needs to scale up task-shared interventions to reduce the mental health treatment gap, thereby increasing access to mental health services.

Conclusion: This study suggests that individuals suffering from schizophrenia could potentially benefit from task-shared PSR interventions. Participants in this study reported that the PSR interventions helped change the way participants think and feel about themselves. The PSR intervention was also reported to facilitate social and economic improvement in some of the participants interviewed, as well as improve their understanding of schizophrenia. This study suggests that task-shared PSR programmes that include families and communities of the affected individuals could potentially help to reduce stigma around schizophrenia and promote integration of patients with schizophrenia back into their communities. From the participants' self-reports, this qualitative study suggests that the PSR intervention was acceptable and beneficial to them. Therefore, studies with a larger sample are recommended to generate objective evidence about effectiveness of PSR programmes in South Africa.

Key words: Task-sharing, schizophrenia, process evaluation, community-based

CHAPTER 1: INTRODUCTION

1.1 Introduction and background

In 2010, mental disorders were considered leading cause of years lived with disability (YLDs) worldwide. Research shows that mental disorders account for 32.4% of YLDs and 13% disability-adjusted life years (DALYs). Furthermore, mental disorders that appear in the top 20 causes of global burden of disease include major depression (second), anxiety disorders (seventh), and schizophrenia (11th) (Vigo, Thornicroft & Atun, 2016). There is a considerable burden of mental disorder in South Africa and this is attributable to high rates of unemployment, crime and violence, drug and substance abuse, the HIV/AIDS pandemic, and child-headed households and poverty (Burns, 2001). In South Africa, mental disorders are placed as a third contributor to the burden of disease (Lund, Petersen, Kleintjes & Bhana, 2012). According to Spedding, Stein, and Sorsdahl (2015), schizophrenia is the third-leading cause of disability in South Africa.

Schizophrenia is a severe and highly disabling mental disorder that is accompanied by considerable impairment in cognitive and emotional abilities, as well as deterioration in social, education, and work functioning, which could possibly lead to long-term disability (Burns, 2012). This disorder is characterized by positive symptoms (hallucinations and delusions), disordered thoughts and speech, severely disorganized behavior (including catatonia, or severe motor slowing), as well as negative symptoms (poverty of thought and speech, avolition, anhedonia, affective flattening) (American Psychiatric Association (APA), 2013). Societies normally devalue, stigmatize, and discriminate against persons with schizophrenia (Barlow & Durand, 2015). As a result, these individuals are excluded from participating in societal and family activities.

Schizophrenia affects about seven people per 1 000 globally (Higashi et al., 2013). This statistic is confirmed by the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, which suggests that the prevalence of schizophrenia is 0.3% to 0.7% globally (APA, 2013). However, Barlow and Durand (2015) report that the prevalence of schizophrenia appears to be approximately 0.2% to 1.5%, which signifies that the disorder is likely to affect about 1% of

the population. In South Africa, 4.8% accounts for YLDs due to schizophrenia (Jack et al., 2014).

Schizophrenia contributes significantly to the burden of mental illness and to health costs. It has been estimated that, in the United States, the annual cost of schizophrenia exceeds \$60 billion (Barlow & Durand, 2015). This mental disorder places a significant burden and has severe consequences for family members of the affected individuals, as well as the affected individual. People with schizophrenia need to be supported by family members which can be a financial burden (Barlow & Durand, 2015). It appears that many patients with schizophrenia are supported by families in LMICs because there are few or limited community based interventions. In addition, research indicates that persons suffering from schizophrenia may lose their jobs since they are unable to work because important areas of functioning in their lives have been affected. This has severe economic implications (Spedding et al., 2015). It can be argued that this is likely to increase the rate of poverty in the country and will reduce the number of economically productive individuals. It has been estimated that the loss of income for South Africans suffering from schizophrenia is close to US\$3.6 billion (Spedding et al., 2015).

Some individuals who have been diagnosed with schizophrenia also have a family history of schizophrenia. This means that patients diagnosed with schizophrenia can inherit a predisposition for schizophrenia (APA, 2013). Twin and family studies have confirmed this hypothesis. In addition, in most cases, environmental factors interact with genetics to produce schizophrenia (Barlow & Durand, 2015). Furthermore, other biological factors that are associated with the onset of schizophrenia include brain damage and abnormal brain development (Cannon, Jones, & Murray, 2002). Research has shown that hyperactivity of dopamine neurotransmitter transmission induces schizophrenia, particularly positive symptoms (delusions and hallucinations) (Kring, Johnson, Davison & Neal, 2010). In addition, cannabis is a drug that is known to induce schizophrenia since it increases dopamine activity in the brain (Koen, Jonathan & Niehaus, 2009). Van Os, Kenis, and Rutten (2010) indicate that the psychotropic component of cannabis causes psychotic symptoms.

Environmental risk factors that could possibly lead to the onset of schizophrenia include being born in winter, parental exposure to infectious diseases, brain damage, paternal age, malnutrition, stress, and maternal diabetes (APA, 2013). Individuals with a history of child abuse or childhood trauma are at risk of developing schizophrenia later in life. Types of abuse that are a risk factor for schizophrenia include neglect, and sexual, emotional, and physical abuse (Franck et al., 2008; Gil et al., 2009).

Schizophrenia is a debilitating and serious chronic condition concomitant with elevated rates of mortality (Bushe, Taylor & Haukka, 2010). This finding is consistent with research results which suggest that people who suffer from schizophrenia are also more likely to commit suicide and die 15 years younger, compared to the general population, due to substance use, diabetics, and cardiovascular diseases (Bradshaw, Lovell & Campbell, 2010). The medication prescribed to psychotic patients is associated with weight gain which increases mortality rates among patients with schizophrenia (Bradshaw et al., 2010). Suicidal ideation is predominant among patients with schizophrenia, and it is estimated that 5-6% of schizophrenic patients die prematurely by their own hands. Furthermore, 20% attempt suicide on one or more occasions (Barlow & Durand, 2015). It appears that long-term use of psychotic medications also increases the risk of cardiovascular diseases and mortality (Scott & Happell, 2011). However, two-thirds of mortality among patients with schizophrenia is attributable to natural causes of death (Auquier et al., 2007).

Historically, patients with schizophrenia or severe mental illness were treated mostly in asylums or psychiatric hospitals. Research suggests that psychiatric hospitals have been associated with human rights abuses and patients becoming institutionalized (World Health Organization (WHO), 2003). According to Chow and Priebe and (2013), psychiatric hospitals are prison-like institutions, even though the inmates have not broken the law, and they share similar characteristics with concentration camps. Furthermore, psychiatric hospitals are a closed system that separates patients from the rest of the community so that they are no longer able to function in the outside world. In psychiatric hospitals, patients' daily activities are regulated by tight schedules and enforced by authority figures (Yohanna, 2013). Goffman, who coined the term 'institutionalized mentality', argued that patients underwent

mortification of the self and that their normal roles for operating in society are taken away in these institutions (Chow & Priebe, 2013).

However, in the mid-1950s, deinstitutionalization of psychiatric patients and outpatient treatment became widespread in many countries (Chow & Priebe, 2013). Deinstitutionalization refers to the process of reducing long stays in psychiatric hospitals, downsizing or closing a large number of psychiatric hospitals, and establishing alternative forms of community mental health services (WHO, 2003b). Deinstitutionalization was influenced by several factors such as the development of antipsychotic drugs and the civil rights movement, which endorsed decentralized community-based care and which motivated discharge of patients from psychiatric hospitals (Yohanna, 2013). Deinstitutionalization emerged in response to human rights abuse and inhuman treatment in psychiatric hospitals. The main goal of deinstitutionalization is to reduce human rights violations, promote social inclusion, mobilize patient support groups, and maximize effective coverage. Deinstitutionalization further aims to reduce relapses through the delivery of PSR programmes suitable for individual's needs, improve treatment adherence, and support family members in providing care for discharged patients (Patel, 2016). Furthermore, deinstitutionalization was endorsed because of the high cost involved in treating severe mental illness in psychiatric hospitals (Chow & Priebe, 2013).

Research suggests, however, that deinstitutionalization has been associated with the development of the 'revolving door syndrome'. The revolving door syndrome occurs when patients are frequently admitted to psychiatric hospitals because of relapses caused by non-adherence, insufficient rehabilitation facilities, and lack of continuity of outpatient treatment and of community-based services (Oyffe, Kurs, Gelkopf, Melamed & Bleich, 2009). Nevertheless, several developed countries have shifted from institutionalization to deinstitutionalization that includes community-based mental health services (WHO, 2003b).

Research shows that a combination of long-term biological treatment and PSR can assist with the clinical improvement of symptoms (Barlow & Durand, 2015). PSR is "a process that facilitates the opportunity for individuals. . .to reach their optimum level of independent functioning in the community" (WHO, 1996, p. 2). It is further recommended that PSR should

include community-based rehabilitation (CBR) (WHO, 1996). CBR is a strategy that is devoted to reducing disability and improving the quality of life and social inclusion of people with mental illness. CBR includes affected individuals, families and community members (Asher, Fekadu, Hanlon, & Mideksa, 2015). Moreover, deinstitutionalization that includes community-based services has been widely considered as a positive approach for increasing accessibility to mental health services in low- and middle-income countries (LMICs) (WHO, 2001). Regrettably, deinstitutionalization in many LMICs has not been accompanied by adequate community-based PSR programmes (WHO, 2014). South Africa is a case in point. While the South African Mental Health Act of 2002 embraces deinstitutionalization, research shows that it is accompanied by few PSR programmes. It appears that the revolving door syndrome will continue to rise because of inadequate PSR programmes resulting from weak implementation of deinstitutionalization policies (Oyffe et al., 2009).

Few studies have attempted to evaluate community-based PSR programmes that require integration of mental health services into Primary Health Care (PHC) in LMICs (Hanlon et al., 2016). In the context of deinstitutionalization in South Africa, where stable patients with severe mental disorders are required to receive their treatment from decentralized PHC facilities (Petersen & Lund, 2011), little is known about the acceptability and effectiveness of this integrated service. Furthermore, little is known about how best to provide adjunct PSR to this service, particularly in outlying areas where such services are scarce.

The aim of this study was to conduct a process evaluation of a task-shared community-based PSR (PSR) intervention for patients with schizophrenia in Dr. Kenneth Kaunda district, North West province in South Africa. The study aimed to explore and explain the experiences of patients with schizophrenia who attended the PSR programme. Furthermore, the study aimed to identify aspects of the programme that were helpful and what can be done to improve the task-sharing PSR programmes. The purpose of this project was to determine how PSR programme assisted families and affected individuals to understand schizophrenia, as well as ways in which the programme facilitated change in behaviour, thoughts, and feelings. Finally, the study aimed to understand how the PSR programme improved socializing, personal hygiene, and treatment adherence among patients with schizophrenia who had attended the intervention.

In the context of a shortage of professional PSR services, the study hopefully provides valuable information about the feasibility and acceptability of using a task-sharing approach since the PSR programme was facilitated by auxiliary social workers. This study is nested in the PRIME project in South Africa. PRIME is a research consortium located in Ethiopia, India, Nepal, South Africa, and Uganda. PRIME aims to generate evidence for implementation and scaling up of integrated treatment for mental disorders in developing countries. In South Africa, the PRIME project is based at Dr. Kenneth Kaunda District of North West province (Lund et al., 2012).

1.2 Statement of the problem

Schizophrenia is one of the most severe and chronic mental disorders that causes clinically significant distress. It is one of the leading causes of disability-adjusted life years worldwide. Therefore, there is a substantial burden imposed by schizophrenia on public health services (Kazadi, Moosa & Jeenah, 2008), with individuals suffering from schizophrenia experiencing social exclusion in society (Balaji et al., 2012). In addition, these individuals may lose jobs which will lead to increased unemployment and drifting into poverty (Fox, 1990).

Research shows that 4.8% of the population suffers from schizophrenia in South Africa, and this is equivalent to 500 000 people. Furthermore, the South African Association of Psychiatrists states that 58% of visits to medical doctors are due to conditions caused or worsened by mental disorders (Trump & Hugo, 2006). The disorder affects individuals' thinking, perception, speech, and movement. Furthermore, schizophrenia affects almost all important areas of functioning such as occupation, interpersonal relations, academic activities, and self-care. Schizophrenia has a devastating effect on the affected individual and family members of affected individuals. Schizophrenia creates an emotional and financial burden to the families affected (Barlow & Durand, 2015). There are grave health implications associated with schizophrenia and they include reduced life expectancy and increased mortality (Burns, 2012), increased rate of cardiovascular diseases due to psychotropic medication (Scott & Happell, 2011), and these people are at high risk for unprotected sexual intercourse and Human Immunodeficiency Virus (HIV) (Auquier et al., 2007).

Biological interventions have been used to treat schizophrenia and they have proved to be successful in managing psychotic patients. Despite advanced medical treatment for schizophrenia, complete recovery is rare (Barlow & Durand, 2015). Deinstitutionalization of psychiatric patients in LMICs has been associated with inadequate community-based care to prevent relapses (Burns, 2011), and to assist with smooth and successful reintegration of patients with schizophrenia back to their communities (Raj, 2012). This suggests weak implementation of the deinstitutionalization policy and that mental health is overlooked in LMICs. Lack of adequate community-based mental health care services has been associated with high rates of relapse and readmission to psychiatric hospitals in developing countries (Oyffe et al., 2009). As a result, the health system spends limited health system resources addressing relapses and readmissions that could have been easily avoided through task-shared PSR programmes that are much cheaper.

Therefore, health-promoting intervention programmes are necessary to prevent mental disorders and promote mental health. PSR programmes are more likely to reduce health costs associated with treating mental illness (Spedding et al., 2015), and revolving door syndrome (Bustillo, Lauriello, Horan & Keith, 2001). PSR interventions are likely to help patients with schizophrenia and family members to understand the condition and to cope with it. PSR interventions have been associated with increased adherence to medication among patients with schizophrenia in developed countries (Acosta, Hernández, Pereira, Herrera, & Rodríguez, 2012). However, little is known about the effectiveness of PSR for schizophrenia in South Africa. In addition, in the context of a shortage of mental health specialists in South Africa, mental health interventions adopting task-sharing

approaches should be evaluated to generate evidence-based interventions. Furthermore, since there are few PSR interventions accompanying deinstitutionalization, little is known about the efficacy and effectiveness of task-shared PSR interventions. Therefore, there is an urgent need to address this gap and to explore ingredients for successful rehabilitation programmes.

1.3 Definition of terms

Schizophrenia is a serious chronic condition which is characterized by positive symptoms (hallucinations and delusions), disordered thoughts and speech, severely disorganized behavior (including catatonia, or severe motor slowing), as well as negative symptoms (poverty of thought and speech, avolition, anhedonia, alogia, affective flattening). (APA, 2013)

Community-based mental health services involve a strategy of community development that furthers the mental health of all community members through the promotion of mental health and prevention of mental disorders. Community-based care services provide accessible, affordable, acceptable, and quality mental health care in the community for people with psychosocial disabilities, aiming at their social integration (WHO, 2001).

Deinstitutionalization is a long-term strategy that considers not only reducing long-stay beds but also ensuring that good-quality care is available in community settings, while shifting tertiary resources towards acute inpatient services and accessible secondary-level mental health services (WHO, 2014).

Psychosocial rehabilitation programmes involve mental health services that bring together approaches from the rehabilitation and the mental health fields, combining pharmacological treatment, skills training, and psychological and social support to clients and families in order to improve their lives and functional capacities (Department of Health (DoH), 2013).

Task-sharing The World Health Organization (WHO) described task-sharing as the rational redistribution of tasks among health workforce teams. When feasible, health care tasks are shifted from more highly trained health workers to less highly trained health workers in order to maximize the efficient use of health workforce resources (WHO, 2008).

Process evaluation: Process evaluation is important in gaining insight into why a successful intervention works and how it can be improved, as well as why an intervention fails or has unexpected outcomes (Faes, Reelick, Esselink & Olde, 2010).

1.4 Outline of the thesis

Chapter Two will cover the impact of schizophrenia, including social drift and causation theory, and the evolution of treatment of schizophrenia. This chapter will explore the evolution of mental illness treatment ranging from an institutional inpatient care model to the introduction of deinstitutionalization of psychiatric patients, and community-based

mental health services care in developed and developing countries. Mental health policy in South Africa such as the White Paper for the Transformation of Mental Health Systems in South Africa, the National Mental Health Policy Framework (MHPF), and Strategic Plan 2013–2020 will be discussed. This chapter will also cover ways in which South Africa has benefited from decentralized mental health care. The chapter concludes by discussing the theoretical framework of complex interventions which is adopted in the study.

Chapter Three discusses research methodology, research objectives, and questions. This chapter will discuss reasons for adopting a qualitative study, using purposive sampling, and thematic analysis. Ways in which data were collected will be included in the chapter. The research site which is DKK in the North West and the structure of PSR programme for patients with schizophrenia which was delivered at the research site will be covered in this section. This will be followed by a discussion of how data was analyzed using N-vivo. This chapter concludes by discussing ethical considerations, credibility, and trustworthiness.

Chapter Four presents the research findings. This section will present ways in which patients with schizophrenia who had attended PSR programme benefited from the intervention. Main themes in this chapter include a change in feelings and thoughts, economic improvement, reducing risky behavior, social skills gained, improvement in personal hygiene and treatment adherence. This part also includes aspects of the intervention that could be improved and aspects of the interventions that were useful. This will be followed by themes highlighting how PSR programme facilitated understanding of schizophrenia among family and community members.

Chapter Five discusses major themes with reference to previous research. This section explains how the PSR programme improved patients' lives. This chapter will start by discussing how the PSR programme assisted patients to change the way they thought about themselves after the program. This part will be followed by a section that explains and discusses how the programme assisted patients to deal with personal problems and situations that were troubling them before joining the intervention. The role of task-shared community-based intervention in reducing risk-taking behavior and non-adherence will be discussed in the chapter. Treatment adherence among patients with schizophrenia is a major problem

around the world. This chapter will explain the role of community-based intervention in reducing high rates of non-adherence. Reducing non-adherence will inevitably reduce the financial burden posed by revolving door syndrome which often results from non-adherence. Encouraging inclusion of patients with schizophrenia in community and family activities will be discussed in this section as one way to fight against social exclusion. It is well known that patients with schizophrenia often do not wash themselves; however, this section discusses how task-shared PSR programmes can improve cognitive and social function which will then result in improved personal hygiene. This chapter concludes by discussing the importance of training and supervision of non-specialist mental health care workers.

Chapter Six concludes the dissertation. This section emphasizes that community-based PSR for individuals suffering from schizophrenia can assist sufferers to cope better with the condition, reduce the revolving door syndrome, and improve quality of life, social skills and family support. This chapter argues that increasing mental health literacy among persons of lower socio-economic status can be achieved through task-shared PSR interventions. South Africa should attempt to implement community-based interventions to improve access to mental health services, and refrain from institutionalization of psychiatric patients since prolonged stays in psychiatric hospitals have been severely criticized because of poor living conditions, violation of human rights, and mortification of the self.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Schizophrenia is a predominant and severe mental disorder that places a significant burden on families as well as the affected individuals. People with schizophrenia need to be supported by family members which can be a financial and emotional burden (Barlow & Durand, 2015). Individuals suffering from schizophrenia have little interest in performing day-to-day functions such as personal hygiene, making them difficult to live with (Chisholm et al., 2008). Patients with schizophrenia may lose their jobs since they are unable to work because important areas of functioning in their lives have been affected. This has severe economic implications for a country and for any dependants of the affected individual (Spedding, Stein & Sorsdahl, 2015).

Biological interventions have been used to treat schizophrenia and they have proved to be successful in managing these patients. However, despite advanced medical treatment for schizophrenia, complete recovery is rare. In addition to medical treatment, PSR programmes can be used to manage schizophrenia (Barlow & Durand, 2015). PSR programmes have been widely considered as an important adjunct approach to treatment for severe mental illness in LMICs and they are especially important to assist with the reintegration of patients with severe mental illness into the community, and improving cognitive functioning and treatment adherence. However, LMICs continue to manage people with mental disorders in mental hospitals, thereby spending their limited scarce resources. This is an ineffective use of resources; in addition, many people with severe mental disorders experience inhumane mental health services (WHO, 2014). This persists despite WHO recommendations that LMICs should adopt deinstitutionalization which includes community-based health services (WHO, 2001). It appears that LMICs continues to manage people with mental illness in psychiatric hospitals due to lack of resources for community based services (Kakuma, et al. , 2011). Lack of resources for community based health services is attributable to inadequate financial resources allocated for mental health in LMICs, and the shortage of mental health specialists who will train and supervise non-specialist workers (Kakuma, et al. , 2011). It can be argued that mental health care services are scarce in LMICs. Task sharing of specialist tasks with generalist health workers has been suggested as a mechanism to increase access to mental

health services, but evidence of the effectiveness of community based services facilitated by non-specialist health care workers is limited, and further studies are required to inform the planning of resource allocation (Kakuma, et al. , 2011).

This chapter will cover the impact of schizophrenia, including social drift and causation theory, and the evolution of treatment of schizophrenia. This evolution discussion will include the institutional inpatient care model and the introduction of deinstitutionalization of psychiatric patients, as well as community-based mental health services care in developed and developing countries. Mental health care in South Africa, which includes decentralization of mental health care services, will also be discussed. This will be followed by a discussion of how South Africa has benefited from decentralized care even though optimal care has not been achieved. It appears that there are few PSR interventions accompanying decentralized care that facilitate the integration of patients back into the community in order to reduce the revolving door syndrome. The chapter concludes by discussing the theoretical framework of complex interventions which is adopted in the study.

2.2 Impact of schizophrenia

2.2.1. Impact of schizophrenia on the individual

Schizophrenia is a chronic mental disorder that affects individual cognitive functioning. Research shows that schizophrenia is associated with cognitive deficits across several cognitive domains (Szöke, et al., 2008). Cognitive deficits across cognitive domains include executive function, attention, working memory, language, processing speed, verbal learning and memory (Świtaj, et al., 2012). Impairment in cognitive functioning often leads to psychosocial disability. Psychosocial disability experienced by patients with schizophrenia includes social functioning (93.75%), vocational disabilities (63.46%), poor personal hygiene (48.08%), educational problems (21.15%), and family problems or divorce (13.9%) (Goreishizadeh, Mohagheghi, Farhang, & Alizadeh, 2012). A systematic review conducted by (Świtaj, et al., 2012) also indicates that schizophrenia causes emotional problems such as depression, anxiety, anger, emotional regulation and hostility.

Individuals suffering from schizophrenia have been perceived as dangerous and unpredictable, prone to self-inflicting harm, not easy to talk to, and irresponsible (Craig at al.,

2008; Wood, Birtel, Alsawy, Pylec & Morrison, 2014). In addition, the stigma of mental illness affects families and individuals affected with schizophrenia. A study assessing stigma perception of patients with schizophrenia and their families suggests that they experience discrimination and exclusion in the context of social relationships with relatives, friends, employers, and colleagues (Schulze, 2007). Patients with schizophrenia also experience exclusion from partaking in community and family activities because of stigma (Balaji et al., 2012), and they are also exposed to different kinds of discrimination in mental health facilities (Solanki, Singh, Midha & Chugh, 2008).

The discriminatory behavior of health professionals is a serious obstacle that creates a barrier to accessing mental health services among schizophrenic patients (Wood et al., 2014). Health professionals' stigma around schizophrenia has made it difficult for caregivers of schizophrenic patients and sufferers to access proper mental health care services (Schulze, 2007). Wood et al. (2014) suggest that some patients with schizophrenia experience overt stigma such as verbal abuse, physical abuse, and loss of friends. Stigma represents a major challenge regarding the integration of persons with schizophrenia into the community. It appears that decentralized mental health care, that includes community-based rehabilitation (CBR) for service users, families, and communities, has the potential to improve psychosocial disability faced by individuals suffering from schizophrenia. Regrettably, there are few decentralized and integrated CBR programmes for patients with schizophrenia and families in South Africa.

2.2.2. Impact of schizophrenia on the family

The family spends a huge amount of money trying to support and assist the family member suffering from schizophrenia (Scott & Happell, 2011). Therefore, schizophrenia has significant financial burdens to the family members or caregivers. However, the financial burden is not merely limited to family members of the affected individuals but also to the health systems and social services in a country (Spedding et al., 2015). In terms of emotional impact, Barlow and Durand (2015) indicate that some parents report that taking care of their schizophrenic family member is a nightmare because some patients keep their family members awake until the early morning. On the other hand, research shows that some family members respond with feelings of guilt, loss, and fear about the future when a family member is suffering from

schizophrenia (Temmingh, Stein & Seedat, 2011). In addition, they have to deal with the stress of coping with social withdrawal or awkward interpersonal behavior, and disturbance of household routine (Spedding et al., 2015). Evidently, this affects family members psychologically and perhaps they may themselves need psychological services to assist their coping with a schizophrenic family member (Temmingh et al., 2011). Caring for patients with schizophrenia has been described as burdensome and involving emotional or psychological, physical, and socio-economic health problems (Chien, Leung, Yeung & Wong, 2013). Therefore, there is a need to increase mental health services through task-shared community-based PSR programmes to help families and community members as well as patients to understand schizophrenia and other common mental disorders. Furthermore, PSR interventions that involve families are likely to improve support system for the affected individual which will then improve emotional difficulties and increase treatment adherence (Pilling et al., 2002).

2.2.3. Impact of schizophrenia on the society

Research suggests that schizophrenia is more common among people of the lowest socio-economic status (Van Os et al., 2010). Werner, Malaspina, and Rabinowitz (2007) also argue that lower occupational and educational status of mothers and fathers and poorer residential area are risk factors for schizophrenia. This suggests that lower socio-economic status is directly associated with high rates of mental illness. The social causation hypothesis indicates that high rates of mental illness in lower socio-economic population groups is mediated by economically stressful conditions (Dohrenwend, et al., 1992). Beside stressful economic conditions, family fragmentation has been found to be associated with schizophrenia. On the other hand, the social drift theory suggests people with schizophrenia may be unable to function because all important areas of functioning have been impaired. This often leads to high rates of unemployment among patients with schizophrenia which leads to drifting into less favorable condition or into lower social classes and poorer areas of the city (Dohrenwend & Dohrenwend, 1970).

2.3 Evolution of schizophrenia treatment

Historically, long-term treatment of patients with severe mental illness (including schizophrenia) was asylum-based mental health care. This model involved institutionalization in 'asylums' or hospitalization in psychiatric hospitals for long periods and patients were generally treated like prisoners. Asylum-based mental health care predominated between 1880 and 1950 in economically developed countries (Thornicroft & Tansella, 1999). This form of care was mainly custodial and the institutions were often overcrowded, and run by poorly trained staff with little medical knowledge. Custodial methods of treatments were punitive and harsh, and included confining patients in dehumanizing conditions, blistering, emetics, beatings, and blood-letting (Thornicroft & Tansella, 1999). Admission to asylum hospitals was often assumed to be a life sentence (Breakey, 1996). Institutionalization of patients with mental illness was welcomed by communities and families who had difficulties taking care of mentally ill relatives (Thornicroft & Tansella, 1999).

2.4 Moral treatment

Moral treatment emerged in response to criticism of asylum-based mental health care conditions which were miserable and inhumane. Moral treatment originated from Phillippe Pinel, an empiricist who established moral treatment principles. He suggested that institutionalized patients should be treated 'normally' (Barlow & Durand, 2015). Pinel highlighted that "when patients were treated in a more dignified and humane manner, they became less violent, less disturbed in their thoughts, and, in some cases, able to be rehabilitated" (Breakey, 1996, p. 18). Through moral treatment, patients gained control over their thoughts and behavior, and patients' morals improved. In this form of care, patients were massaged, and had the opportunity to listen to soothing music. Patients suffering from severe mental illness were freed from chains utilized to confine them. Consequently, the emergence of moral therapy made custodial care more therapeutic (Barlow & Durand, 2015).

2.5 The reform of the asylum and the decline of moral therapy

Nineteenth century America was characterized by population growth, mobility, industrialization, and urbanization. During the early decades of the century, it was established that the state should take care of patients with mental illness, particularly those who were

poor. This resulted in the establishment of state hospitals. Establishment of state hospitals was strongly associated with Dorothea Dix who advocated improvement of conditions for individuals suffering from mental illness (Breakey, 1996). Due to the rapid growth in the number of individuals suffering from mental illness, moral therapy declined because it worked well only in institutions that had fewer patients, which provided an opportunity for individual attention.

In response to overcrowding and increased demand for treatment, many mental health hospitals resorted to restraining and confining mentally ill patients, rather than providing therapeutic activities (Breakey, 1996). It appears that the increase in persons suffering from mental illness resulted in a transition from moral therapy back to custodial care because mental hospitals were overcrowded and understaffed (Barlow & Durand, 2015). Several other factors led to the decline of moral therapy. One was that the state had difficulties in providing funds to ensure sustainability. Another reason for the decline in moral therapy was the influx of immigrants. Many immigrants had difficulties adjusting in the United States and the prevalence of mental illness was high among this population. Overcrowding led to a deterioration in the quality of care in state hospitals; treatment provided was often harmful, dehumanizing, and staff was poorly trained. Furthermore, moral therapy was impractical in the state hospitals that were understaffed (Thornicroft & Tansella, 1999).

The Mental Hygiene Movement emerged in response to the dehumanizing conditions in the state hospitals. This movement wanted to improve conditions or humanize the care of patients suffering from mental illness, and to eradicate the human rights abuses and brutalities in the state hospitals (Barlow & Durand, 2015). The Mental Hygiene Movement wanted to achieve early diagnosis and treatment, and develop adequate hospitalization for the patients (Bertolote, 2008). This movement had its origin in the work of Clifford Beers who had suffered from bipolar disorder and was hospitalized in different hospitals for the insane. In a book titled *A Mind That Found Itself*, Beers described his experiences in the state hospitals (Breakey, 1996). He explained that he was exposed to ill-treatment and harsh conditions in psychiatric hospitals. This led him to recognize the need to reform treatment in the state hospitals and to develop better methods for treating patients there.

Beers spent most of his time formulating a reformation plan for the Mental Hygiene Movement. Part of the movement included interventions that addressed stigma about mental illness. Beers argued that it was necessary to educate society and raise awareness that mental illness is the same as physical disease, and it was not worse to suffer from dementia praecox (now known as schizophrenia) than tuberculosis (Bridges, 1928).

The Mental Hygiene Movement was also concerned with the prevention of mental illness. However, implement of prevention interventions was impossible because little was known about the causes of mental illness. As a result, disciplines such as sociology, psychology, psychiatry, and physiology were encouraged to investigate the causes of mental illness. Research findings from these disciplines provided a better understanding of mental illness and the ways in which psychiatric disorders could be prevented and treated (Bridges, 1928). Two schools of thought in the social sciences that attempted to explain environmental causes of mental illness included psychoanalysis developed by Sigmund Freud (1856–1939), and this was followed by behaviorism. Psychoanalysis postulated that early childhood experiences led to the development of mental illness. Behaviorism maintained that learning and adaptation can cause mental illness, particularly learning undesirable attitudes or irrational beliefs (Barlow & Durand, 2015).

Subsequent to the Great Depression in 1929 and World War II, living conditions in the state hospitals deteriorated significantly. Violation of human rights, poor conditions in the psychiatric hospitals, and institutionalization of psychiatric patients persisted. However, prolonged stays in psychiatric hospitals were severely criticized (Thorncroft & Tansella, 1999). Goffman argued that in ‘total institution’, patients undergo mortification of the self (Chow & Priebe, 2013). Total institution refers to a situation where the inmates are under the complete control of the institution (e.g. a prison). Institutionalized patients underwent mortification of the self, which included a process whereby the individual was stripped of their past societal and family roles to take on purely institutional roles (Goffman, 1961).

Goffman (1961) further argued that psychiatric hospitals create a closed system that separates patients with mental illness from the rest of society and/or they have limited access

to the outside world. Institutionalized patients are isolated from society for long periods of time and their behavior is dictated by institutional rules. Individuals in institutional care are constantly under supervision to ensure compliance with rules. A study of prolonged stay indicated that poor living conditions in the state mental hospitals were responsible for increased presenting symptoms or problems, and psychiatric hospitals caused even more harm to patients (Breakey, 1996).

2.6. Deinstitutionalization

Criticism of state hospitals resulted in political involvement with new mental health guidelines and legislation, discussions of alternative forms of mental health, and provision of mental health funds for new psychiatric paradigms. As a result, a new psychiatric paradigm accompanied by deinstitutionalization of psychiatric patients was established (Novella, 2010). This approach to mental health care is characterized by prevention of inappropriate psychiatric hospital admissions through provision of community mental health care centers; it also encourages as short a stay in psychiatric hospitals as possible (WHO, 2003c), release to the community centers of all stable institutionalized patients, establishment of community support systems for stable patients, and admission to psychiatric hospitals only if community-based care fails (Thornicroft & Tansella, 1999).

The new policy for mental health care that included deinstitutionalization was influenced by several factors including the civil rights movement, which advocated for treating patients in the least restrictive settings that are not harmful or dehumanizing (Chow & Priebe, 2013). It has also been argued that deinstitutionalization was enabled by the introduction of psychotropic medication which stabilized patients sufficiently for them to be cared for in the community (Breakey, 1996). The financial burden of inpatient mental health care also influenced the introduction of deinstitutionalization (Chow & Priebe, 2013).

Deinstitutionalization largely reflects an international movement from asylum-based mental health care to community-based mental health services. These reforms were promoted by the WHO in the mid-1950s in the United States and the United Kingdom and later in Europe and Scandinavia (Novella, 2010). The psychiatric reform programmes resulted in the passing of the Mental Health Act of 1959 in the United Kingdom, the Community Mental Health

Centers Act of 1963 in the USA, and the 1975 passing of the German Enquête Commission (Breakey, 1996).

Deinstitutionalization of mental health care services has been associated with a significant decline in psychiatric hospital beds. The majority of the older mental health hospitals were closed, with new mental health departments being established in general hospitals (Novella, 2010). The closure of psychiatric hospitals in the United States was legislated by the Community Mental Health Centers Act of 1963, and strict standards were passed so that only individuals who were at risk of harming themselves or a danger to someone else could be admitted to state psychiatric hospitals (Thornicroft & Tansella, 1999). In addition, several countries have established outpatient and day patient services. Outpatient services include community-based treatment facilities. These comprise community mental health care centers and multidisciplinary community-based psychiatric teams including psychiatrists, psychologists, community health care workers, general practitioners, and community psychiatric nurses.

The consequences of deinstitutionalization of psychiatric patients have been substantial in developed countries (Novella, 2010). The length of stay in psychiatric hospitals has declined and a considerable increase in the discharge of patients has been observed (Novella, 2010). By the mid-1960s in the United States, many patients had been moved from psychiatric hospitals to community-based mental health centers. The number of institutionalized patients fell from 560 000 in the 1950s to 130 000 by 1980 (Breakey, 1996). By 2000, the number of state psychiatric hospital beds per 100 000 people was 22, down from 339 in 1955 (Lamb & Weinberger, 2005). Voluntary admission in many countries has increased, and admission is made into general hospitals, rather than into psychiatric hospitals (Novella, 2010).

Research suggests that community psychiatry is based on the hypothesis that patients suffering from mental illness can be best treated when the bonds with their family, society, and friends are maintained (Breakey, 1996). Similarly, according to the WHO, patients suffering from mental illness should:

Always be treated and cared for in settings having the lowest impact on their personal freedom, status, and social rights, including their ability to continue working and conducting their daily lives. In practice, this means promoting community-based attention and to resort to institutional treatments only in exceptional cases. (WHO, 2003a, p. 43).

2.7. Community/psychosocial management of schizophrenia

Schizophrenia is a chronic mental illness. However, it is a manageable condition because of advances in biological treatment and psychosocial support. Research shows that a combination of long-term biological treatment and psychological interventions can assist with the clinical improvement of symptoms (Barlow & Durand, 2015). The WHO also recommended PSR as an auspicious approach for schizophrenia treatment. The WHO states that PSR should include community psychoeducation about schizophrenia, address stigma and discrimination and integration of mental health services into primary care services (WHO, 1996). The WHO recommends deinstitutionalization of psychiatric patients (WHO, 1996) which encourages provision of symptom management of stabilized patients through antipsychotic medication and PSR programmes in community health care centers to promote recovery. PSR interventions for schizophrenia aim to improve functionality and build protective factors and promote social inclusion (Craig, 2006). It is absolutely essential that empirically validated community-based PSR Programmes are incorporated into the treatment of patients with schizophrenia, to improve their social functioning and residual symptoms (Bustillo et al., 2001).

Intensive Case Management (ICM) has been recommended to provide long term care for patients with schizophrenia who do not require immediate admission. ICM originated from Assertive Community Treatment (ACT) and Case Management (CM) community models of care (Dieterich, Irving, Park, & Marshall, 2010). ACT and CM are community-based health services which were established in the 1970s for severely mental ill patients discharged from closing psychiatric hospitals. ICM is offered on the community level and aims to assist patients with schizophrenia to acquire materials like medical care, shelf clothing, and food (Burns, 1999). Furthermore, ICM encourages the inclusion of patients with schizophrenia in community activities and assist them with coping skills required to participate in community

activities, and ensuring continuity of care amongst treatment agencies (Burns, 1999). ICM has been found to be effective in reducing hospitalisation and improving psychosocial disability among patients with schizophrenia. ICM encourages small case load and high intensity input whilst ACT is referred as a team-based case management and also involves a multidisciplinary team (Dieterich et al., 2010). It can be argued that ICM and ACT are not feasible in LMICs because of inadequate financial resources for mental health services, and shortage of mental health specialists and high treatment gap.

Research shows that psychoeducation intervention for schizophrenia are effective in addressing several psychosocial disabilities faced by patients with schizophrenia. According to Cochrane systematic reviews psychoeducation interventions for schizophrenia play a vital role in improving treatment compliance, reducing relapses and the revolving door syndrome, increasing patients' knowledge and understanding of their condition, and improves social functioning (Xia, Merinder, & Belgamwar, 2011) Psychoeducation refers to educating a person with a psychiatric disorder to improve their understanding of the condition. In addition, psychoeducation interventions that include families and communities can reduce stigma around mental illness, facilitate smooth re-integration of psychiatric patients back to their communities and improve treatment adherence. (Xia, Merinder, & Belgamwar, 2011).

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There is robust evidence which supports the effectiveness of other PSR programmes in promoting recovery among patients with schizophrenia. The Schizophrenia Patient Outcomes Research Team (PORT) project has developed and disseminated evidence-based PSR

programmes for schizophrenia. Treatment guidelines for schizophrenia established by PORT were initially published in 1998 and revised in 2003 (Kreyenbuhl, Buchanan, Dickerson & Dixon, 2010). Evidence Review Groups (ERGs) reviewed over 600 studies to identify evidence-based PSR programmes for schizophrenia. These interventions include assertive community treatment (ACT); supported employment; cognitive-behavioral therapy; family-based services; token economies; skills training; PSR programmes for alcohol and substance use disorders; and PSR programmes for weight management (Kreyenbuhl et al., 2010).

ACT and family-based interventions particularly have been found to be effective in reducing relapses, rehospitalization, and homelessness among patients with schizophrenia. Family interventions that encourage patients with schizophrenia to have ongoing contact with their family members and friends tend to increase antipsychotic adherence and reduce psychotic symptoms (Kreyenbuhl et al., 2010). Research suggests that a majority of patients with schizophrenia do not adhere to treatment and this has serious health implications (Barlow & Durand, 2015). It has been estimated that non-adherence in schizophrenia patients ranges from 20% to 89% with the median rate for non-adherence being 55% (Acosta et al., 2012; Barkhof, Meijer, de Sonnevill, Linszen & de Haan, 2012). These statistics reflect the seriousness of non-adherence; this requires the attention of mental health professionals and should be addressed urgently to improve the quality of life of affected individuals.

Higashi et al. (2010) argue that non-adherence has been reported globally and it is the most challenging aspect of treating schizophrenic patients. The Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study reports that 74% of patients discontinue the prescribed medication within 18 months (Lieberman, 2005), and Acosta et al. (2012) reports that 53.6% of patients with schizophrenia stopped or refused to take antipsychotics within the first year of diagnosis. However, Higashi et al. (2010) reports that some patients stop treatment instantly after discharge. Non-adherence to prescribed treatment is attributable to intolerable side effects, refusal to take treatment, lack of illness insight or cognitive impairment, substance abuse, and medication beliefs (Higashi et al., 2010).

Non-adherence to medication has a negative impact such as relapse, dangerous behavior, suicide or attempted suicide, arrest, alcohol and drug consumption, poorer prognosis,

rehospitalization, loss of jobs, longer time to remission, psychiatric emergencies, and poor mental performance (Acosta et al., 2012). Lack of family and community support increases incidences of non-adherence; for example, some patients with schizophrenia live alone which increases the risk of not taking prescribed medication (Acosta et al., 2012).

The implications of non-adherence contribute to the already high costs of schizophrenia to the health system (Lieberman, 2005). Consequently, non-adherence to antipsychotic medication can have a considerable negative impact and exacerbate the condition and functioning of patients with schizophrenia, and create a further financial burden for the health system as well as for the family. Reducing non-adherence to medication has the potential to improve the lives of affected individuals, and to reduce the cost of health care services significantly (Higashi et al., 2010).

Community-based PSR programmes can be used to improve adherence since they increase mental literacy. As a result, community and family members will understand mental illness and support their relatives, friends, and community members suffering from schizophrenia. According to Barlow and Durand (2015), PSR programmes have been found to be effective in increasing adherence to medication and improving lives of affected individuals. It appears that knowledge gained from community-based PSR programmes enables patients with schizophrenia to understand their illness and cope with it more effectively. Further, evaluation of PSR programmes indicates that adherence to treatment improved by 20%, and that in interventions that included family members, adherence improved by 70% (Haddad, Brain & Scott, 2014).

PSR programmes have been found to be effective in reducing psychotic symptoms and improving long-term outcomes such as remission, deterioration of the disorder, and recovery from schizophrenia (Chien et al., 2013). It appears that PSR programmes are likely to improve adaptive functioning which increases the chances of employability or return to work or school, if studying. In addition, community-based PSR programmes have the potential to reduce relapses (and the revolving door syndrome) through increasing adherence to treatment (Bustillo et al., 2001). PSR interventions not only directly address symptom

reduction and improve prognosis and relapse rates, but also offer a more cost-effective treatment for schizophrenia (Chien et al., 2013).

In economically developed countries, PSR programmes have been a central part of comprehensive mental health treatment rendered to patients with schizophrenia since the 1980s (Bharathi, Huang & Lu, 2011). Pontes et al. (2013) also argues that several community-based PSR programmes have been implemented in Europe, the United Kingdom, and the United States, and most of these interventions are effective. ACT delivered in the United States in the 1990s has been shown to be effective in reducing rehospitalization and increased community service at a reduced cost (Chien et al., 2013). In Australia, it has been reported that psychosocial ACT interventions do not only reduce symptoms and readmission but also improve housing and quality of life for patients with schizophrenia (Bond, Drake, Mueser & Latimer, 2001).

Community rehabilitation services studies reviewed in the Netherlands suggested improvement in the quality of life and social functioning among patients with schizophrenia (Chien et al., 2013). These findings are consistent with Clarke et al.'s (2000) randomized trial of two ACT programmes, which suggests that ACT reduces readmission to psychiatric hospitals by 78% and increases housing stability by 67%, improves quality of life by 58% and improves psychiatric symptoms by 44% among schizophrenic patients in economically developed countries. However, in developing countries, few community-based mental health services that accompany deinstitutionalization have been implemented.

2.8 Psychosocial rehabilitation in the LMIC context

The UN Convention postulates that comprehensive rehabilitation services including social services, employment, health, and education are needed “to enable people with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life” (UN 2008, article 26 as cited in Lemmi et al., 2016, p.16). Community-based rehabilitation (CBR) interventions are also recommended by the World Health Organization (WHO) for addressing the mental health needs of people in LMICs. CBR interventions were established for LMICs for community

development and provision of rehabilitation programmes that aim to improve the quality of life for individuals suffering from mental illness, as well as for their families and communities (Iemmi et al., 2016; WHO, 2010).

The concept of CBR was established in the late 1970s (Iemmi, et al., 2015) as an auspicious approach for delivering PSR programmes for individuals suffering from mental illness in LMICs and as a promising strategy to accomplish 'health for all'. CBR is implemented by government and non-government organizations (NGOs) through the joint efforts of the affected individuals, their families, and communities. CBR provided within communities typically utilizes local resources (Iemmi, et al., 2015).

In 2010, a CBR matrix was developed to provide directions on how CBR interventions should be developed and implemented (WHO, 2010). This framework demonstrates a need to intervene in different aspects of life and it has five components: health, education, social, livelihood, and empowerment. However, a CBR intervention is not anticipated to implement every component of the CBR framework since not all individuals with disabilities need support in every component of the matrix (Iemmi et al., 2015). The health component of the CBR framework focuses on health promotion, prevention of illness and rehabilitation (WHO, 2010), and improved knowledge about health (Iemmi et al., 2015). On the other hand, the social components focus on helping individuals with mental illness to fulfil social roles and responsibilities in their communities and families, and to be treated as equal members of society, thereby addressing stigma against people with mental illness and encouraging inclusion of persons with mental illness in community activities (Iemmi et al., 2015).

Few countries among LMICs have implemented and then evaluated the effectiveness of CBR. One study evaluated the effectiveness of an Assertive Community Treatment (ACT) programme which was implemented in Cape Town, South Africa. This showed positive results in relation to improved social functioning and reduced rehospitalization in the intervention group (Botha, Koen, Joska, Hering & Oosthuizen, 2010). Asher, Fekadu, Hanlon, and Mideksa (2015) evaluated the Rehabilitation Intervention for people with Schizophrenia in Ethiopia (RISE) and found the intervention to be effective in improving social and occupational functioning and economic status. The RISE intervention assisted patients with schizophrenia

to return to work, increased access to health care services, reduced prevalence of chaining of patients with schizophrenia through access to treatment (Asher et al., 2015).

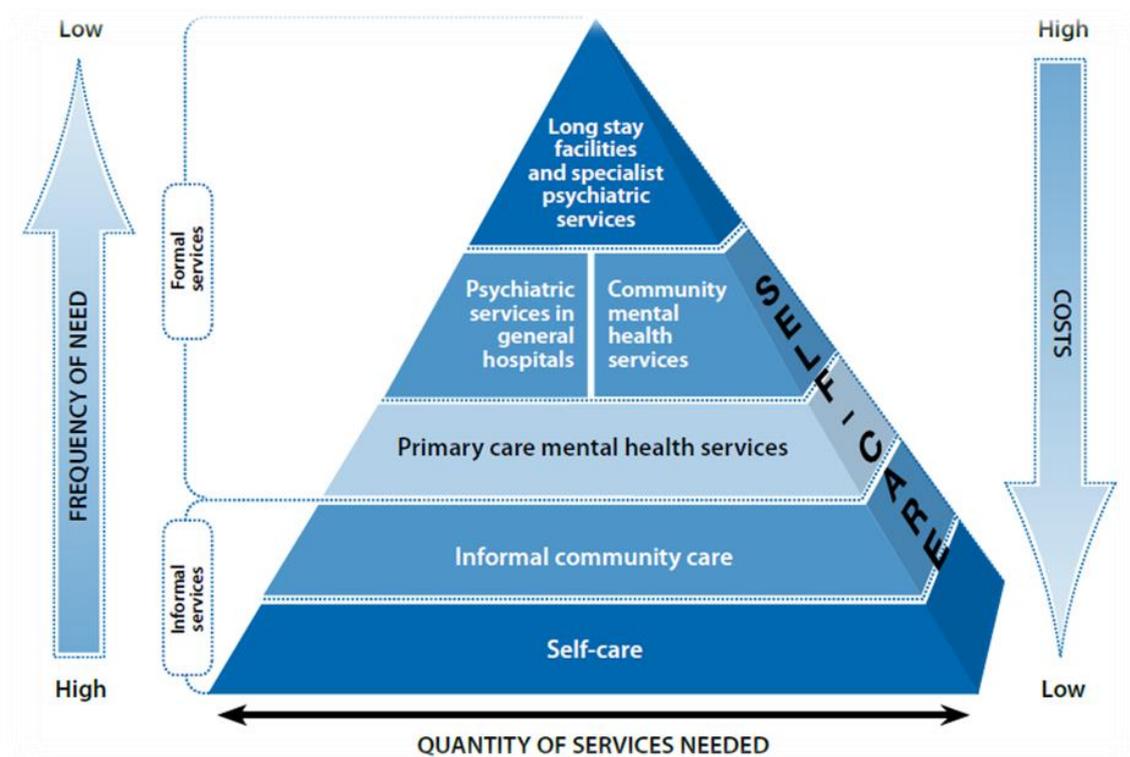
Group counseling in Jinan and Shanghai in China delivered to families of individuals with schizophrenia reported a 10.4% lower rate of relapse and 6.4% lower rate of hospitalization in the intervention group (Zhang, He, Gittelman, Wong & Yan, 1998). These results are consistent with those of Ran, Leff, Hou, Xiang, and Chan (2003) who evaluated a CBR intervention in Chengdu, China, and found that 85% of participants recovered fully compared to those in the control group, the relapse rate was lower in the intervention group, and treatment adherence was six-fold more likely in the intervention group compared to control group. This study also reported a decrease in stigma against individuals with schizophrenia. Chatterjee, Patel, Chatterjee, and Weiss (2003) evaluated the effectiveness of a CBR intervention for patients with schizophrenia in Barwani in India and found the intervention to be effective in reducing psychiatric symptoms after 12 months.

A Cochrane review that included nine studies on CBR for schizophrenia indicated that CBR coverage is very low and evidence for its effectiveness needs to be examined in the consideration of scaling up of these interventions in LMICs (Iemmi et al., 2015). Low coverage of CBR can be attributed to the lack of funding, and the lack of funding often leads to lack of sustainability of already implemented interventions. The CBR interventions in LMICs are mostly concentrated in urban areas and are not distributed according to the needs of people (Saraceno et al., 2007). The lack of CBR interventions in LMICs is also attributable to a shortage of mental health specialists and this also contributes to the treatment gap (Iemmi et al., 2015).

In response to the high treatment gaps, the WHO developed a model describing an 'Optimal Mix of Mental Health Services' (Figure 1) intended to improve access to mental health services in LMICs (WHO, 2009). This pyramid-shaped model recommends limiting the number of psychiatric hospitals or mental health specialists' services, and simultaneously establishing mental health services in general health care and communities, incorporating mental health services into PHC (WHO, 2009). In addition, the model seeks to establish informal community mental health services and promote self-care at the base of the pyramid (WHO, 2009). Self-care should be supported by formal health services. The formal sector should play a

fundamental role in educating people within their communities about how to deal with mental illness effectively, and provide effective strategies for addressing conflict management and relationship problems, and the risks of alcohol and drug use. Self-care must be facilitated through all levels of the pyramid (WHO, 2009). Therefore, community-based interventions are likely to play a fundamental role in promoting self-care.

Figure 1: WHO’s Optimal Mix of Mental Health Services taken directly from (WHO, 2009, p. 22)



Source: WHO (2009)

The first level of care within the formal health system includes PHC and this should provide mental health services. This level involves early diagnosis and treatment of mental disorders, managing stabilized psychiatric patients, counseling and referral to another level when necessary, and mental health prevention and promotion activities. Mental health interventions at PHC should be provided by non-specialists under the supervision of mental health specialists. Services provided at PHC level are easily accessible, acceptable, and affordable for communities. Integration of mental health services into PHC will improve access to health services, and mental disorders will be identified and treated in the early

stages of development (WHO, 2009). Furthermore, Hanlon et al. (2016) support the integration of mental health services into PHC since this will address the unmet needs of the population in LMICs. Availability of mental health services in PHC and community health centers signifies that people will not have to travel long distances to receive proper health care.

The WHO further postulates that a single-service setting is less likely to improve access to mental health services, thus information-sharing and education, collaboration, support, and supervision across different levels of care are fundamental to any health system. It is suggested that all countries should endeavor to generate the best possible mix of services from all different levels of the pyramid and frequently evaluate the effectiveness of the mix. In addition, integration of mental health services has the potential to address the shortage of mental health specialists, improve access, and reduce stigma (WHO, 2009).

At the core of the WHO recommendation is the decentralization and deinstitutionalization of health services so that interventions and health services are located where they are needed most and are more accessible, namely at the PHC level (Spedding et al., 2015). Strong community mental health services are a fundamental part of deinstitutionalization and to avoid unnecessary hospitalization. Persons getting good community mental health care have better overall health, mental health outcomes, and improved quality of life compared to those treated in psychiatric hospitals (WHO, 2009). It appears that community mental health delivers care that respects the rights of people with mental illness, while the majority of people prefer community services to hospital care (Lund & Flisher, 2009). Furthermore, research suggests that community-based interventions are likely to increase mental health literacy and enhance health-seeking behavior while also reducing defaulting and human rights abuses in mental health hospitals (Petersen & Lund, 2011).

2.9. Task-sharing

The WHO established Mental Health Gap Action Programme (mhGAP) which aims to scale up PSR interventions for severe mental disorders such as schizophrenia and to reduce the burden

of mental disorders in LMICs. The WHO's mhGAP recommends that treatment and management of schizophrenia should include PSR interventions because they are cost-effectiveness, feasible and acceptable (WHO, 2011; WHO, 2008). Since LMICs are currently experiencing inadequate financial resources and limited human resources, the WHO's mhGAP recommended task-sharing as a feasible approach for improving access to mental health services and reducing a 32% treatment gap for individuals with schizophrenia (WHO, 2008) .

Task-sharing refers to "rational redistribution of tasks among health workforce teams where specific tasks, when appropriate are moved from highly qualified health workers to workers with shorter training and qualifications in order to make more efficient use of the available human resources" (WHO, 2008, p. 2). This means nurses and doctors must provide mental health services at the PHC level, and they should receive training and supervision from mental health specialists such as psychologists and psychiatrists prior to rendering mental health care services in PHCs and community settings (WHO, 2008).

Scholars have suggested expanding the role of psychiatric nurses, psychologists, and psychiatrists from service delivery to mental health leadership to address the treatment gap in developing countries. The potential leadership roles include designing and managing mental health interventions, supervision of non-specialists, ensuring quality assurance of mental health services, capacity-building in PHC settings, and providing consultations and referrals (Patel, 2009). Since task-sharing also involves training of community health workers (CHWs), CHWs can recognize and identify people suffering from mental illness in their communities and refer them to PHC centers for further assessment, diagnosis, and treatment. Health care professionals working in PHC centers will then provide comprehensive mental health treatment that involves antipsychotic medication and PSR programmes (Mendenhall et al., 2014). Furthermore, trained community health workers or lay counsellors can provide preventative interventions at PHC level or community settings, and hence increase accessibility to mental health services for people with schizophrenia (WHO, 2003a).

The majority of LMICs have accepted and endorsed task-sharing. A study exploring feasibility and acceptability of task-sharing of mental health care in providing mental health services in LMICs investigated perceptions of primary health care providers (nurses, physicians, CHWs),

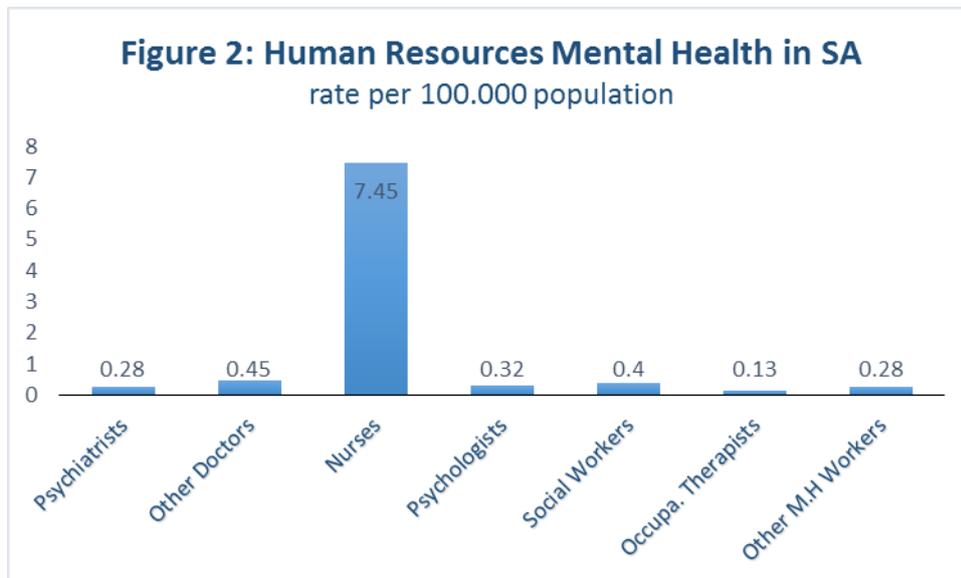
service users, and community members in five countries (Ethiopia, India, Nepal, South Africa, and Uganda) participating in PRIME (Mendenhall et al., 2014) The research findings showed that a task-sharing approach to mental health is perceived to be feasible and acceptable provided that the following conditions are met: 1) increased access to medication and human resources; 2) satisfactory training and strong supervision at the PHC level; and 3) adequate remuneration for health professionals partaking in task-sharing mental health services. This acceptability has the potential to reduce significantly the treatment gap and increase access to mental health services. The introduction of task-sharing and integration of mental health services will reduce unnecessary referrals and increase access to mental health services at PHC and community level (Mendenhall et al., 2014).

It appears that task-shared CBR has the potential to reduce the revolving door syndrome in LMICs that is typically caused by relapses due to inadequate support services at the community level. Furthermore, research has shown that task-shared PSR interventions for schizophrenia improve quality of life and adaptive functioning, while reducing the economic burden posed to the health system, and affected individuals and families (Bharathi & Huang, 2011; WHO, 2011; Asher et al, 2015). However, evidence for effectiveness of CBR for schizophrenia is limited in LMICs (Brooke-Sumner, et al., 2015). Therefore, there is a need to scale up task-shared PSR interventions for individuals with schizophrenia in LMICs and to evaluate those interventions to generate rich knowledge about evidence-based interventions. Furthermore, evidence-based interventions will allow other researchers in LMICs to implement and replicate CBR programmes that have been evaluated and found effective in managing and treating schizophrenia.

2.9 Psychosocial rehabilitation – the South African context

It appears that South Africa is one of the developing countries that suffer from a shortage of human resources to deal with mental illness (Figure 2). Lund et al. (2012) argue that 75% of people who live with common mental illness do not have access to mental health services in South Africa. Mental health human resources working in the Department of Health or NGOs is 9.3 per 100 000 population. In addition, the breakdown of human resources working in public mental health facilities in South Africa per 100 000 is as follows: 0.28 psychiatrists, 0.4

other medical doctors (not specialized in mental health), 7.45 nurses, 0.32 psychologists, 0.4 social workers, 0.13 occupational therapists, and 0.28 other health or mental health workers (including non-specialists such as primary health care workers, health assistants, medical assistants, and professional and paraprofessional psychosocial counsellors) (WHO, 2008).



Source: WHO (2008)

The South African government has made a considerable effort to reform and improve access to mental health services. The White paper for the Transformation of the Health System in South Africa (DoH, 1997a), the National Health Policy Guidelines for Improved Mental Health in South Africa (DoH, 1997b), and the Mental Health Policy Framework and Action Plan (2013-2020) were introduced to address mental health with the aim of downsizing psychiatric hospitals and developing community-based care. However, it appears that the Mental Health Policy and Guidelines lack clear objectives and this resulted in weak implementation (Burns, 2011).

The Mental Health Care Act (MHCA) 2002 was adopted and promulgated in 2004. The MHCA was established to improve access to mental health care, and improve the human rights of mental health care users (Stein, 2014). The MHCA suggested decentralized, integrated, and community-based care services which aim to increase accessibility of psychotropic medication in general hospitals and at PHC level, as well as the provision of CBR programmes

(Petersen & Lund, 2011). Mental Health Review Boards have been established to protect human rights for mental health care users in regional and district hospitals. The 72-hour observation period was introduced to increase accessibility and availability of mental health services in South Africa and decrease unnecessary referrals to psychiatric hospitals (Petersen & Lund, 2011). However, there is a shortage of mental health specialists for the 72-hour management and observation period, and the infrastructure is also inadequate in some provinces in South Africa (Lund, Kleintjes, Kakuma & Flisher, 2010).

A study by the Mental Health and Poverty Project indicates that South Africa benefited from the decentralization of mental health care services (Lund et al., 2008). Some provinces in South Africa endorsed integrating mental health services into PHC. Those provinces benefited from decentralization through training of PHC nurses to provide mental health services that were previously not available in PHC, and this assisted in scaling up access to mental health services. PHC nurses are now allowed to continue prescriptions but not allowed to initiate prescriptions, except in the case of emergency (WHO, 2014). Notwithstanding, through decentralization, psychotropic medication is available at outpatient and inpatient facilities, and in some PHC facilities (Lund et al., 2010). Availability of psychotropic medication in PHC facilities and general hospitals increased access to mental health services in provinces that implemented the decentralization policy.

The burden that was imposed by referring mentally ill patients to tertiary hospitals has been reduced through decentralization. However, optimal benefits of decentralization have not been achieved because of a shortage of mental health professionals and poor training of non-specialists in general hospitals and PHC (Petersen & Lund, 2011), inadequate community-based care, and a continued heavy reliance on psychiatric hospitals (Lund et al., 2008). Lund et al. (2010) argue that, on the provincial level in South Africa, there is a weak policy implementation and this needs to be addressed urgently.

Recently, an Integrated Chronic Disease Management (ICDM) model has been established in South Africa and this model endorses integration of mental health services into PHC (Asmall & Mahomed, 2013). The Mental Health Policy Framework (MHPF) and Strategic Plan 2013–2020 was established in 2013 and this new policy recommends task-sharing and integration

of mental health services into PHC. It appears that in South Africa, the MHPF is regarded as the first official mental health policy that has the potential to implement the Mental Health Care Act of 2002. Furthermore, MHPF integrates evidence-based practices which support service user human rights (Marais & Petersen, 2015). Petersen, Bhana, and Baillie (2011) also argue that to address the treatment gap and scarcity of mental health professionals, there is a need for task-sharing.

Few studies adopted a task-sharing approach to the provision of PSR programmes in South Africa. The studies that do exist provide evidence of the potential effectiveness of task-sharing PSR programmes for common mental disorders. Outcome evaluation of a 12 week Interpersonal Therapy (IPT) group intervention facilitated by community health workers (CHWs) in Hlabisa in the northern part of KwaZulu-Natal reported a notable improvement in the intervention group (Petersen Lund, Bhana & Flisher, 2012). Furthermore, a group-based IPT intervention that was delivered by lay counsellors in eThekweni District in KwaZulu-Natal indicated that the intervention group showed considerable improvement after three months (Petersen, Hanass-hancock, Bhana & Govender, 2014). A brief intervention that was delivered by lay counsellors in Cape Town in the Western Cape aiming to address depression, and alcohol, tobacco and other drug use in antenatal care in South Africa indicated that there was a decline in tobacco use, and depression (Sorsdahl et al., 2015).

The Mental health Societies in Gauteng and the Western Cape deliver PSR intervention for persons with severe mental illness which has not been evaluated and covered by published research (Central Gauteng Mental Health Society, 2017). Lack of evaluation of this PSR intervention can be attributed to inadequate financial resources and shortage of mental health professionals in South Africa. A systematic review conducted by (Brooke-Sumner, et al., 2015) suggests that task-shared PSR programmes for schizophrenia can reduce relapses and rehospitalisation, improve treatment adherence, quality of life, social functioning, symptomatology and knowledge about schizophrenia. A systematic review (Brooke-Sumner, et al., 2015) suggests that task-shared psychosocial interventions for schizophrenia can reduce relapses and rehospitalisation, improve treatment adherence, quality of life, social functioning, symptomatology and knowledge about schizophrenia. A systematic review of randomised control trials for psychosocial interventions for schizophrenia in LMIC highlighted

an improvement in social functioning. Other studies that suggest effectiveness of psychosocial interventions for schizophrenia in LMICs include family interventions in South Africa and Iran (Asmal, et al., 2011; Koolae & Etemadi, 2010 (13; Botha et al., 2010). While these studies generate preliminary evidence to highlight effectiveness of CBR interventions for schizophrenia in LMIC, little is known about the effectiveness of task-sharing PSR interventions that deal with schizophrenia in South Africa.

2.10 Challenges with decentralization of mental health care services in South Africa

Despite decentralization, there is still a treatment gap in terms of CBR interventions for chronic mental disorders, mental health promotion and prevention programmes, and accessibility to health services for mental illness (Petersen et al., 2012). As a result, the majority of mental disorders remain unidentified and untreated in PHC level (Petersen & Lund, 2011). Decentralized mental health services need to be accompanied by PSR interventions for deinstitutionalization to be successful (Lund et al., 2008). However, it appears that there are few PSR programmes at a community level that accompany decentralization of mental health care (Petersen & Lund, 2011). Deinstitutionalization of psychiatric patients back to their communities without adequate PSR interventions is irresponsible and a violation of service user rights (Lund et al., 2008), and inadequate PSR programmes often cause the revolving door phenomenon (Petersen & Lund, 2011).

Task-sharing is an alternative approach that can be used to address CBR service gaps (Petersen et al., 2009). Research shows that few studies have been conducted on the benefits of task-sharing PSR interventions for schizophrenia in LMICs, including South Africa (van Ginneken et al., 2013). This is consistent with Hanlon et al.'s (2016) finding which indicates that few studies have attempted to evaluate community-based PSR programmes that require integration of mental health services into PHC in LMICs. Therefore, mental health interventions that adopt a task-sharing approach need to be evaluated to explore their acceptability and the ingredients for successful task-shared interventions. In the context of deinstitutionalization in South Africa, where stable patients with severe mental disorders are required to receive their treatment from decentralized PHC facilities, little is known about the

acceptability and effectiveness of interventions that integrate mental health services for schizophrenia into PHC through task-shifting.

Furthermore, a Cochrane review that included five studies on community-based rehabilitation for schizophrenia indicated that task-sharing interventions lack robust evidence for schizophrenia in LMICs (Iemmi et al., 2015). Therefore, there is a need to conduct research on decentralized community-based PSR programmes for schizophrenia delivered through task-sharing in South Africa. This study aimed to address this gap by conducting a process evaluation of a task-sharing community-based PSR programme for patients with schizophrenia attending PHC facilities for their ongoing medical treatment. This community-based PSR was delivered by auxiliary social workers (ASW) in DKK district, North West Province (Brooke-Sumner et al., 2015).

2.11 Theoretical approach: Complex interventions

This study will adopt the methodology of evaluating complex interventions. Complex interventions are generally described as public health interventions that comprise several interacting components which work together to produce desired change (Craig et al., 2008). Furthermore, complex interventions are utilized to evaluate many areas of public health that use complementary and alternative therapies, health promotion, and rehabilitation (Paterson, Baarts, Launsø & Verhoef, 2009). The evaluation of complex interventions focuses on establishing the effectiveness of public health interventions, fine-tuning the intervention, and delivering it more efficiently. It explores how the intervention works and identifies the active ingredients that make the intervention effective or ineffective (Craig et al., 2008). The Medical Research Council (MRC) proposed a framework for the evaluation of complex interventions to assist researchers when evaluating public health interventions. The MRC framework comprises four different elements, namely, development, feasibility and piloting, evaluation, and implementation (Faes, Reelick, Esselink & Olde, 2010).

This dissertation is located within a formative phase and focuses purely on the process evaluation part of the MRC framework since the aim of this study is to conduct a process evaluation of the PSR programme delivered within the PRIME project. The evaluation consists

of understanding the change processes (Faes et al., 2010). Understanding the change processes is an important aspect of evaluation and focuses on exploring and investigating the ways in which the intervention was implemented. Process evaluations can provide important information about why an intervention has unexpected outcomes or fails. Furthermore, it allows the researcher to explore in detail parts of the intervention that were useful and factors that contributed to the failure of the intervention. Finally, process evaluation can provide an understanding of why an intervention works and how it can be enhanced (Craig et al., 2008; Faes et al., 2010). To achieve this process evaluation, semi-structured interviews were used to explore in detail aspects of the PSR that were helpful and contributed to the success of the intervention. Furthermore, participants were asked to outline aspects of the programmes that were not helpful and to suggest what could be done to optimize the intervention.

2.12 Conclusion

Schizophrenia is debilitating disorder and has severe economic and emotional implications on the affected individuals and families. Schizophrenia is more common amongst people of lower socio-economic status. Furthermore, individuals suffering from schizophrenia may drift into poverty because may be unable to function at work because of cognitive impairment. This section discussed the evolution of treatment of schizophrenia in developed and developing countries. Evolution of treatment if schizophrenia that was discussed in this chapter included institutional inpatient care model and the introduction of deinstitutionalization of psychiatric patients, as well as community-based mental health services care. Furthermore, the evolution of mental health in South Africa that was discussed included the introduction of the White Paper for the Transformation of Mental Health Systems in South Africa, the National Mental Health Policy Framework (MHPF), and Strategic Plan 2013–2020.

Historically patients with schizophrenia were treated mostly in psychiatric hospitals. Psychiatric hospitals have been severely criticized. Deinstitutionalisation and community-based PSR programmes have been recommended in response to criticisms and shortage of mental health specialists in LMICs. This chapter suggested that South Africa has benefited

from decentralized care. However, there are few PSR interventions accompanying decentralized mental health care needed to facilitate the integration of patients with schizophrenia back into the community to reduce high rates of revolving door syndrome.

This chapter also discussed the importance of task-sharing in addressing a 75% mental health treatment gap in South Africa. Several studies suggest that task-shared interventions are cost effective and increase access to mental health care services. It was argued in this chapter that there are few studies that evaluated a task-shared intervention for service user suffering from Schizophrenia in South Africa. Therefore, studies are needed to address this gap. This section concluded by discussing complex interventions which was a theoretical framework adopted in the study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Objectives of the study

This study had the following objectives:

1. To understand participants' experiences of attending the PRIME psychosocial rehabilitation intervention.
2. To explore helpful aspects of the psychosocial rehabilitation programme.
3. To investigate aspects of the intervention that could be improved.
4. To explore the perceptions of schizophrenic patients toward the facilitators.
5. To explore how the intervention helped the family and community to understand schizophrenia.

3.2 Research questions

In order to reach the objectives of the study, the following research questions were formulated:

1. What were the experiences of patients with schizophrenia who attended psychosocial rehabilitation intervention?
2. What were the helpful aspects of the psychosocial rehabilitation programme?
3. What were the parts of the intervention that could be improved?
4. What were the perceptions of patients with schizophrenia toward facilitators?
5. How did the intervention assist the family and community to understand schizophrenia?

3.3 Research design and theoretical approach

This study adopted a qualitative approach in order to gain insight into the experiences of psychosis patients. A qualitative approach was imperative primarily because it is usually employed to understand and explain the social world in which people live, why people behave the way they do, and how attitudes and opinions are formed (Creswell, 2003). In this study, this approach was appropriate because it enabled patients with schizophrenia who had attended the PSR programme to provide their insight into their feelings, attitudes, and experiences about attending the intervention. Furthermore, the qualitative approach enabled patients with schizophrenia to explain in detail how the programme changed their lives, which

aspects of the programme were useful, what skills were gained by attending a support group, and how counselling assisted patients in dealing with personal problems.

3.4. Research site

The study site was Dr. Kenneth Kaunda District (DKK) located in the southern part of the North West Province in South Africa. DKK consists of four sub-districts, and they include Tlokwe City Council, City of Matlosana, Maquassi Hills, and Ventersdorp. The predominant economic activities in DKK involve mining and agriculture. The majority of the people in DKK speak Setswana and the population is approximately 695 934 (Statistics South Africa, 2012). The sample was drawn from psychosis patients attending Grace Mokhomo and Kanana Orkney clinics of the City of Matlosana sub-district of DKK district. Grace Mokhomo is a large community health clinic, whilst Kanana Orkney clinic is a small clinic in the Matlosana sub-district.

The PSR programme was informed by the experiences and needs of service users with schizophrenia and their caregivers from the DKK district (Brooke-Sumner et al., 2015). In addition, the PSR programme included document review and consultation with a psychiatric nurse and a psychiatrist rendering PSR services in other provinces in South Africa. As a result, a learning-based training manual for a five-day training workshop for facilitators of the intervention was developed. A facilitator guide for auxiliary social workers (ASWs) explaining the activities for each group session was also developed. The intervention included 12 sessions for service users, delivered weekly by ASWs, and five sessions for caregivers (Brooke-Sumner et al., 2015).

Table 1: Topics for each session with the service users and caregivers

| Service user sessions | Caregiver sessions |
|--|--|
| <ul style="list-style-type: none">• Introduction to programme and goal-setting• Understanding our schizophrenia diagnosis• Understanding medication• Coping with schizophrenia• Substance abuse• Knowing ourselves• Income-generating activities; managing anger, stress, and conflict• Dealing with stigma and discrimination• Money management• Contributing to the household• Closure session | <ul style="list-style-type: none">• Understanding our relative's illness• Coping with caring for a person with schizophrenia• The effect of conflict on the family• Dealing with stigma and discrimination• Caring for the caregiver |

3.5 Sample and sampling method

This study used secondary data from the Programme for Improving Mental Health Care (PRIME). PRIME is a research consortium located in Ethiopia, India, Nepal, South Africa, and Uganda. PRIME aims to generate evidence for implementation and scaling up of integrated treatment for mental disorders in developing countries. In South Africa, the PRIME project is based at Dr. Kenneth Kaunda (DKK) District of North West province, South Africa (Lund et al., 2012). This study used data that was collected in DKK. This data was collected to understand the experiences of patients with schizophrenia who attended the PSR under the PRIME project.

A purposive sample of 16 stabilized patients with schizophrenia receiving follow-up medication in Grace Mokhomo and Kanana Orkney clinics in the Matlosana sub-district of DKK district were recruited to participate in the study. Twelve out sixteen were males. Only two participants were married. The level of education for participants ranged from Grade one to

Grade eight and only one participant had no formal education. Furthermore, the majority of participants were unemployed while others had temporary employment.

3.6 Data collection

Data was collected using one-on-one, face-to-face, semi-structured interviews. Data was collected by trained interviewers with a B. Psych qualification in participants' home language (Setswana). Furthermore, the interviewers were independent of the intervention. The semi-structured interview provides opportunities for both interviewer and interviewee to discuss some topics in more detail than in a questionnaire. Furthermore, it allows the interviewer to probe the interviewee to elaborate, especially if the interviewee is providing brief responses and ambiguous answers (Hancock, Ockleford & Windridge, 2007). The interview questions (Appendix B) were intended to elicit and understand the experiences of service users and aspects of the intervention that were helpful, as well as things that require improvement in the PSR. Furthermore, interviews were audio-recorded with research participants' consent.

3.7 Data analysis

All audio-recorded interviews were transcribed then translated from Setswana into English. Thematic analysis using N-vivo software was used to analyse qualitative data. Thematic analysis is a qualitative analysis technique that involves identifying and analysing themes. Themes are important because they capture something paramount about the data in relation to research topic (Braun & Clarke, 2006). The first step of thematic analysis involved reading the transcripts to get a feel for the data. The next step was to start looking in detail at the data to start identifying themes, and the lists of themes were identified. Themes identified matched each objective of the study. Lists of themes were used to develop a coding manual. N-vivo software was used to organize the data and store codes. The coding scheme was then entered into N-vivo and a framework for coding was generated. Codes were entered into N-vivo as nodes and data was then coded. Data representing codes was then matched with corresponding codes. The final stage was to identify overarching themes to be utilized for discussing findings.

3.7.1 Credibility and trustworthiness

To ensure reliability and validity, and robustness and rigor of the study, the research protocol and interview guide (Appendix A) were developed to ensure that this study could be replicated by another researcher. The research protocol included research questions and objectives that are consistent and the field workers remained focused during data collection to ensure that responses were consistent with the research questions and objectives. Furthermore, internal validity was achieved through probing during the interviews.

Triangulation analysis can be used to achieve reliability and validity of the research findings (Wong, 2014). Triangulation involves utilizing more than one source of data, investigators or methods to study a single phenomenon and cross-examine the research findings (Yeasmin & Rahman, 2012). This is important mainly because it generates evidence from different sources to elucidate findings (Creswell, 2013). The credibility and trustworthiness of this study was achieved through triangulation analysis by another PRIME project researcher. This was done to ensure accuracy, fairness, and confirmation of the description and analysis of the research report (Wong, 2014). The study included thick and rich descriptions of the participants' themes or accounts to support the findings, thereby allowing the reader to see the world through the eyes of the participants. This study also used multiple sources of data such as interviews and literature, to contradict or support the interpretation and to elucidate perspectives and themes. Furthermore, to ensure data checking the research supervisor and the PRIME researcher checked themes and coding.

3.8 Ethical considerations

The nature of the study was explained in Setswana for those not fluent in English. Criteria for participation in the study was a confirmed diagnosis of schizophrenia. In addition, all research participants were assessed using mini status exam as well as the Brief Psychiatric Rating Scale (BPRS) and assessment of cognition by a clinical psychologist. Participants were provided with an informed consent form (Appendix B) explaining the aims of the study prior to participating.

Information on rights to confidentiality, limits to confidentiality, and anonymity was explained to the participants. Further, participants were informed that interview transcriptions would be seen by PRIME researchers and pseudonyms would be used instead of personal identifying information when direct quotations were used to illustrate some of the arguments.

Participation in the study was purely voluntary and no person was advantaged or disadvantaged in any way for choosing to participate or not to participate in the study. Participants were informed about their right to withdraw from the study at any point during the interview and their right to refuse to answer any question. Participants who could possibly become distressed during the interview would have been referred to Dr. Von Wiellig, the psychologist at the clinic. PRIME project ethical approval was obtained from the UKZN Biomedical Research Ethics Committee (BREC) (Appendix C). Even though this study was nested within the larger PRIME project it had to apply for its own ethical clearance from the BREC. Ethical clearance for this study was also obtained from the UKZN BREC (Appendix D).

CHAPTER FOUR: RESEARCH FINDINGS

4.1 Introduction

This study utilized thematic analysis to identify frequently occurring themes in the interviews. Themes identified were based on the aim of the study which was to understand experiences of patients with schizophrenia who had attended a PSR programme the Dr. Kenneth Kaunda district. This chapter will present the themes which emerged from the interview and these are illustrated by relevant direct quotes. This section will begin by presenting themes highlighting experiences of the PSR programme which addresses the first research question. This part will be followed by themes highlighting helpful aspects of the intervention and aspects that could be improved. Themes of how the PSR programme facilitated understanding of schizophrenia among family and community members will be presented as well. This chapter concludes by presenting themes highlighting the participants' perceptions of the facilitators.

4.2 Change in feelings and thoughts

This theme focuses on how the PSR programme helped change the way participants think and feel about themselves. Ten out sixteen participants reported that the PSR programme changed the way they thought and felt. Feelings and thoughts of participants post the intervention are illustrated in the following quotes.

Participant 1: *Like I told you, when you understand that you have a mental illness and how it came about and being able to recognize symptoms, you are able to take rightful decisions.*

Participant 3: *Because I have this illness, the people treated me badly; they would say I am sick and "nobody should take me seriously", but now those comments do not affect me. Every time I attend the groups, I feel lighter and I am still taking my medication. I felt really better.*

Participant 8: *I am now not embarrassed to tell them that I have a mental illness. So when they ridicule me, it makes no difference because I have accepted the fact that I have this illness. So being a part of this group helped me a lot.*

Participant 14: *I felt bad because people told me that I was crazy. In counseling, they told me that I am not crazy. I feel good.*

4.3 Most helpful aspects of the intervention

The majority of the patients with schizophrenia reported that the PSR programme improved their lives. The PSR programme assisted participants to deal with and solve personal problems they had prior to attending the intervention. Sub-themes derived from the overarching theme included social improvement, reducing risky behaviour, economic improvement, and understanding their illness.

4.3.1 Social improvement

Eleven out of sixteen participants indicated that the counselling programme helped them to deal with personal problems and/or situations that were troubling them prior to joining the group. The intervention improved the problem and socializing skills for patients with schizophrenia. The following quotes illustrate this.

Participant 1: Now, I no longer give people problems; I arrive at home on time. If I want food, I make myself food.

Participant 7: It changed my behaviour; I normally sat in the house and did not interact with others outside.

Participant 8: Like I said, I avoided socializing; nowadays I approach others and talk to them. They once asked us to pick an animal that resembles us and I chose hare because it is shy. But now I am no longer shy; I can speak my heart out.

Participant 2: Being part of the support group taught me how a person is, and to have empathy towards another person, that I shouldn't laugh at someone who has a problem but I should rather try to build him/her the way I was built in the groups. To love your fellow just as you love yourself, respect others like you respect yourself, and take no one for granted.

4.3.2 Social exclusion

This theme looked at how participants experienced discrimination, stigma or social exclusion prior to the PSR programme. Five out of sixteen reported that they experienced exclusion from community activities and could not participate in household activities. However, after

the intervention some participants did not experience exclusion in the family and community. The following quotes illustrate how the intervention helped participants with social exclusion.

Participant 6: *I could not do certain jobs that require lifting heavy things, attending a community meeting and participating in household activities like cooking.*

Participant 14: *They used to discriminate [against] me because they said I was a thief and a mad man.*

4.3.3 Reducing risky behaviour

Patients with schizophrenia sometimes engage in risk-taking behaviour. Participants reported that there was a change in their risk-taking behaviour after participating in the intervention. Eight out of sixteen indicated that they stopped stealing, fighting, and using substances. The following quotes highlight how the PSR reduced risk-taking behaviour.

Participant 1: *I no longer roam the streets late at night. Now I don't have a lot of problems.*

Participant 8: *Stopping violence at home and making friends in the community.*

Participant 10: *I used to fight a lot, but now I rarely fight.*

Participant 12: *I have never drunk nor smoked since I started groups.*

Participant 14: *I do not fight anymore and I resist peer pressure to steal cables at the mines. Now I can resist associating with bad company; I relate well to others. I work at home and attend meetings in the community. I also sell things to make extra money.*

4.4 Economic improvement

4.4.1. Generating income

The majority of participants who had attended the PSR programme felt that the support group had been very beneficial and helpful since they learned skills that would enable them to start small businesses, make budgets, and other skills that would help them to generate an income. The following quotes indicate how the PSR programme improved the lives of participants economically.

Participant 1: *Previously, I used a lot of money for things I could (have done) myself; like now I can plant my own vegetables, grow them here at home, and eat them rather than spending money to go buy them elsewhere.*

Participant 2: *The session on generating income was useful to me. I love money and that information helped me a lot. I had started selling some things but currently had to stop because of my relapse.*

Participant 3: *I really enjoyed a session where they taught us how to make gardens. I learned what I can do to earn money and improve my life and that I can save money by planting vegetables at home.*

Participant 5: *They taught us income-generating activities like selling fruits, making gardens; how to take care of the little money we had. Since then, I have started a small garden and budgeting.*

Participant 6: *The group session on generating income was very helpful to me since they taught us to start selling fruits and vegetables.*

Participant 9: *There is a lot I learnt. Now I do handy jobs.*

Participant 14: *They taught us how to make gardens and sell our products from the garden, and selling sweets and chips and other things. I have been thinking about starting a small business; is just that I do not have money to start.*

4.4.2. Budgeting

Some of the participants reported that they could not budget prior to joining the intervention. However, after the intervention, there was a change in the ways in which they spend their money and they started budgeting.

Participant 14: I now budget and stick to my budget. I used to use my money carelessly. I use my money for important things like food and tools.

Participant 15: I have started budgeting and saving so that I buy clothes for myself. I never used to do that.

4.5 ‘Understanding our illness’

The session that focused on explaining schizophrenia was reported as an important aspect of the intervention. Prior to attending the intervention, some participants did not understand

that schizophrenia is manageable and what was happening to them as part of their illness. The following quotes highlight the importance of understanding schizophrenia as a helpful aspect of the intervention.

Participant 3: *They explained the illness we had in great depth and now I know what is happening to me.*

Participant 6: *Information on our illness and treatment was very helpful.*

Participant 7: *Being taught about our illness. After that, we experienced changes such as understanding ourselves and knowing ourselves.*

Participant 14: *We have gained good teachings about schizophrenia. It was helpful to discover that schizophrenia is manageable.*

Participant 16: *The parts where I was taught more about my illness was helpful.*

4.6 Skills gained

This part presents another aspect of the experiences of patients with schizophrenia who had attended PSR intervention. The majority of participants reported that they acquired important skills in the PSR intervention. 'Skills acquired' was identified as an overarching theme. The sub-themes under this overarching theme include socialising skills, personal hygiene, and budgeting.

4.6.1 Social skills

A number of participants started to socialize and establish meaningful relationships after participating in the intervention. The following quotes illustrate how the PSR programme improved socializing skills for patients with schizophrenia.

Participant 8: *I learnt that one can get better by talking. Talking and telling others what your problem [is] helps a great deal. It does not help being shy.*

Participant 10: *I can now sit with others at the clinic and talk to others.*

Participant 12: *I have a new girlfriend now. The group helped me to approach other people because I could not talk to anyone.*

4.6.2 Personal Hygiene

Personal hygiene is one of the challenges facing individuals with schizophrenia. Some of the patients with schizophrenia reported improvement in personal hygiene after attending the PSR intervention. Prior to joining the intervention, some participants reported that they could not wash themselves, their clothes, dishes, etc. The following quotes highlight how personal hygiene improved after the intervention.

Participant 5: *Counselling did make things a little better. Like I said, I previously spent days without bathing, but now I know that I should bath.*

Participant 8: *I never used to take care of myself e.g. I did not bath and I would often be reminded. Nowadays I do it without any reminder. Now I also garden.*

Participant 11: *I wash my clothes, sweep, wash dishes and take care of myself.*

Participant 12: *I did not take care of myself; now I take care of myself and look for piece jobs.*

Participant 15: *I can now clean the house which I never did.*

4.7 Treatment adherence

When individuals with schizophrenia do not take their medication regularly, they are susceptible to experiencing relapses. Participants who had attended PSR interventions reported that the intervention assisted them to understand the importance of taking medication regularly. The following quotes illustrate themes about adherence.

Participant 4: *They helped me to adhere to my medication.*

Participant 5: *I now know that I should clean, cook, and take my medication.*

Participant 7: *She [the facilitator] emphasized the need to adhere to treatment.*

Participant 9: *I learnt that this illness requires one to adhere to treatment at all times.*

4.8 Aspects of the intervention that could be improved

This theme concerns aspects of the intervention that participants suggested could be improved. However, the majority of participants reported that nothing could be improved and what was done was adequate. Only a few had suggestions on what could be changed or improved in the PSR intervention. The following quotes illustrate this theme.

Participant 3: *She should change the way she asks questions, because the questions were challenging.*

Participant 15: *[More] information on mental illnesses because there are different mental illnesses, and what causes mental illnesses.*

4.9 Family and community

This theme focuses on the impact of the PSR programme on family and community members of Dr. Kenneth Kaunda district. The sub-themes reflect family and community members' understanding of schizophrenia, the roles and activities patients with schizophrenia engaged in since attending the intervention, and how community and family members treated patients with schizophrenia subsequent to the intervention. Further, acceptance of the PSR programme also emerged during data analysis.

4.9.1 'Family and community understand your illness'

Thirteen out of sixteen participants reported that being part of the PSR programme helped people in their families and community to understand schizophrenia. The following quotes indicate that being part of the group was a positive experience for patients with schizophrenia, since it empowered their family and community members with a better understanding of schizophrenia.

Participant 3: *The people in my community are actually happy to have me around, and they understand my illness. At first, they treated me badly because I am sick, but not anymore.*

Participant 5: *In the beginning, they thought I was just being stubborn, but now they understand my condition.*

Participant 7: *They understand me and the community members understand my illness. They have stopped treating me like a mad man. They have learnt that I have feelings and I get hurt if I am mistreated.*

Participant 8: *They understand us better now. We now feel free and we easily disclose our illness to community members.*

Participant 9: *They understand that when one does not adhere to treatment, it gets worse and that [schizophrenia] is chronic. But it is manageable just like diabetes and high blood pressure.*

4.9.2 Roles and activities

In most cases, patients with schizophrenia were not allowed to participate in family and community activities because of stigma concerning their mental illness. The PSR programme played an important role in assisting patients with schizophrenia to start engaging in family and community activities. This is noted in the following quotes.

Participant 3: *I could not work and cook for myself now I can ... I went to church ... and I never attended church before.*

Participant 11: *I wash my clothes, sweep, wash dishes and take care of myself. I am called at school to pack boxes and they give me money in return.*

Participant 9: *I used to spend most of my time at home doing nothing; now I can go out there and do casual labor, as well as the garden. Also now I am learning how to weld and how to work with metal.*

Participant 12: *Gardening and washing my clothes. I never used to do these before the group. People also call me to come and do handy jobs such as painting.*

4.9.3 Change in how they were treated by family and community members

It emerged from the data that there was a change in the ways in which community and family members treated some of the patients with schizophrenia. Four out sixteen participants reported the change. The following quotes illustrate how this change occurred.

Participant 6: *They treat me alright, especially since being part of the group and they even give me money sometimes.*

Participant 8: *They no longer look down at me like they used to. Now they treat me well. They listen to me now.*

Participant 12: *People have stopped saying bad things to me like I am "mad and useless". They treat me well and they relate well to me. Initially, they would ridicule me; now since I started attending the group, they are very nice because they know about the groups.*

Participant 14: *I relate well with my community and family members. They treat me like a normal person and they do not call me like a mad man; they see that I have changed. They know how to spot changes in my behaviour.*

Participant 16: *They no longer say that I am crazy; they do not say negative things.*

4.9.4 Acceptability of PSR programme in the community

This part looks at the acceptability of the intervention. Thirteen out of sixteen participants reported that the intervention was accepted and they mentioned different reasons for this acceptance. The following quotes illustrate acceptability of the intervention.

Participant 3: *The illness was explained to them, and we were happy about that.*

Participant 6: *it was accepted because they teach us important things, and the community is proud of that.*

Participant 8: *They understand us better now. We now feel free and we easily disclose our illness to community members.*

Participant 14: *They realized that the groups were important for us, because they see that I have changed.*

4.10 Perceptions of patients with schizophrenia toward facilitators

Patients with schizophrenia reported that the facilitators of the groups were well trained and the information that was given by facilitators was very useful. Fifteen out of sixteen participants reported that facilitators were well trained and passionate about their job. This is illustrated in the following quotes.

Participant 1: *She knew how to convey the information she had.*

Participant 2: *They look like they were trained enough; they understand what they are doing.*

Participant 5: *I was comfortable with her; we even told her when we did not understand her.*

Participant 6: *She always asked us questions after explaining something to see if we understood what was being discussed.*

Participant 7: *She was very encouraging and she would come check us at our homes.*

Participants also stated that facilitators were confident and organized.

Participant 7: *She was very organized because she took her time to explain and managed time very well.*

Participant 8: *She was well organized; she did it with passion and she never looked down upon us.*

4.11 PSR as a good way to support people with schizophrenia

Patients with schizophrenia who had attended the PSR programme reported that PSR programme was helpful in supporting individuals suffering from schizophrenia. Fifteen out of sixteen participants reported that the support group is one way of supporting patients with schizophrenia. The following quotes highlight this finding.

Participant 14: *We have gained good teachings about schizophrenia and ways of generating income. So I think it is a good way to support people with schizophrenia because they will get to know their illness very well and ways of supporting themselves.*

Participant 15: *It is a good way because people with this illness need support.*

4.12 Recommending the PSR programme

Recommending the PSR programme to another person was another theme that emerged from the data. All participants reported that they would recommend the intervention to other community and family members suffering from schizophrenia. This theme illustrates the positive impact the PSR programme had had on the patients with schizophrenia. The following quotes highlight reasons for recommending the intervention to other persons.

Participant 3: *So that they find out what is going on with them because it will be explained.*

Participant 7: *Yes, so that they understand their illness better.*

Participant 9: *I would recommend to those who are not coming so that they will find out about a lot of things they may not be aware of.*

Participant 14: *So that they ... learn more about this illness and adhere to medication.*

Participant 15: *I would recommend the ... program because people with schizophrenia need support.*

Another fundamental theme that emerged was that patients with schizophrenia relished participating in the PSR programme and were not happy that it ended. Fifteen out of sixteen participants reported they would like to continue to participate in the PSR intervention. This is demonstrated by the following quotes.

Participant 6: *I enjoyed participating in the group and I would like to continue because they teach us a lot of important things.*

Participant 14: *I would like to continue because I would, later on, teach others about schizophrenia.*

4.13. Conclusion

This section presented research findings of the study and major themes were demonstrated with relevant direct quotes. Thematic analysis was used to identify frequently occurring themes that described experiences of patients with schizophrenia who had attended the PSR programme in the DKK district, North West province. Research results in this study highlights effectiveness and significance of a task-shared intervention. The majority of participants reported that PSR programme facilitated understanding of schizophrenia which improved insight into their condition. The PSR programme played a vital role in improving personal hygiene, socializing skills and reducing risk behavior among patients with schizophrenia.

Participants reported that the program facilitated understating and the importance of treatment adherence. This chapter also presented themes suggesting that the PSR programme improved community and family understanding of schizophrenia which will play an important role in improving support system for the affected individuals. This section further presented themes demonstrating that the program was well accepted by participants and community members. The study findings suggest that community-based PSR intervention could potentially be a beneficial approach for supporting individuals with schizophrenia.

CHAPTER FIVE: DISCUSSION OF RESULTS

5.1. Introduction

This chapter explains the research findings with reference to previous literature. Research findings will be explained and discussed in relation to the research problem and research objectives. LMICs are currently experiencing a shortage of mental health specialists and South Africa is no exception to this with a treatment gap of 75% for common mental disorders (Petersen & Lund, 2011). It is evident that many people suffering from mental disorders remain untreated in LMICs as well as in South Africa. In response to the shortage of mental health specialists, the WHO recommended task-sharing as an approach to address the shortage of mental health professionals and reduce the treatment gap. Furthermore, task-sharing has also been embraced by the South Africa National Mental Health Policy Framework and Action Plan (Marais & Petersen, 2015).

In addition to task-sharing, the South African Mental Health Act of 2002 endorsed decentralization of mental health care services. Furthermore, the Act motivated for deinstitutionalization of psychiatric patients that is accompanied by PSR programmes. In South Africa, while discharged psychiatric patients receive medication in PHC clinics, there are few PSR programmes accompanying deinstitutionalization. Research suggests that inadequate PSR is strongly associated with high rates of the revolving door syndrome (Oyffe et al., 2009) and this creates a financial burden to the already struggling health system in South Africa. Furthermore, there are too few mental health specialists to deal with the revolving door syndrome.

One way to address the shortage of PSR programmes is through task-sharing. There have only been a few studies that have attempted to evaluate task-shared PSR interventions with individuals suffering from schizophrenia in South Africa (Asmal, et al., 2011; Koolae & Etemadi, 2010; Botha et al., 2010). The purpose of this study was to address this gap by conducting a process evaluation of a task-sharing community-based PSR programme for

patients with schizophrenia attending PHC facilities for their ongoing medical treatment in Dr. Kenneth Kaunda district, North West province. The study, therefore, adds to the body of evidence on task-shared community-based PSR for schizophrenia in South Africa.

The objectives of the study were aimed at understanding five important aspects of the intervention:

- To understand participants' experiences of attending the PRIME psychosocial rehabilitation intervention.
- To explore helpful aspects of the psychosocial rehabilitation program.
- To investigate aspects of the intervention that could be improved.
- To explore the perceptions of schizophrenic patients toward the facilitators.
- To explore how the intervention helped the family and community to understand schizophrenia.

5.2. Change in feelings and thoughts

The findings of this study indicate a crucial role that can be played by task-shared community-based PSR programmes for individuals suffering from schizophrenia. Change in feelings and thoughts addresses the first research question which was intended to understand participants experiences of the PSR. It was evident from the research findings that the PSR programme improved patients' lives and patients reported positive experiences of the program. Patients with schizophrenia who had attended the PSR programme indicated that, after attending the intervention, there were remarkable changes in the ways in which they thought and felt about themselves and their condition. People with schizophrenia are often told that they are crazy and they typically feel embarrassed and humiliated about this. Participants reported that they were no longer humiliated and embarrassed when people said they are crazy and stupid after attending the intervention.

This finding is consistent with Petersen et al.'s (2014) research findings which suggest that task-shared intervention plays a pivotal role in reducing internalized stigma and this change reduces withdrawal and social isolation among affected individuals. Furthermore, another

study exploring acceptability and feasibility of task-sharing reported that PSR programme facilitated by non-specialists can reduce stigma (Mendenhall et al., 2014). The findings of this study suggest that the PSR programme equipped participants with coping strategies that assisted them to deal with internal and external stigma. The intervention improved their self-esteem and enabled patients to see themselves as normal human beings in their communities. Petersen et al. (2014) postulates that task-shared intervention that includes sessions on internalized stigma improves patients' self-esteem and self-concept, and leads to reduced suicidal thoughts and negative thinking.

5.3. Most helpful aspects of the intervention

Most helpful aspect of the intervention addresses the second research question. Helpful aspect of the intervention included improved problem-solving skills and social improvement, economic improvement, social improvement, reducing risky behaviour and treatment adherence.

5.3.1. Problem solving skills and social improvement

It appears that the PSR programme assisted patients with schizophrenia to deal with personal problems and/or situations that were troubling them prior to joining the group. The findings indicate that socializing and problem-solving skills were found to be particularly useful. Respondents indicated that they had previously avoided socializing or social situations; they would normally stay at home the whole day. It is well documented that schizophrenia impairs social skills (Barlow & Durand, 2015). It appears that social deficits among patients with schizophrenia can elicit stressful interactions which can lead to social isolation and withdrawal (Chien, Leung, Yeung, & Wong, 2013). Furthermore, social isolation and withdrawal is likely to cause emotional problems which can exacerbate schizophrenia. However, acquiring socializing skills through the PSR programme helped to overcome their social isolation and establish meaningful relationships. One participant went so far as to indicate that he managed to get a new girlfriend because the program had informed him about the importance of socializing and how to approach people. This is consistent with

previous research which suggests that PSR interventions facilitate improvement of interpersonal and communication skills and community re-integration (Chien, et al., 2013).

Furthermore, the participants learned that talking to and telling other people their problems helped to make them feel better. Research suggests that community-based rehabilitation for schizophrenia that includes social skills training has the potential to improve social skills for individuals suffering from schizophrenia (Kopelowicz, Liberman & Zarate, 2006). This was established and supported by the research findings in this study.

Kopelowicz et al. (2006) have shown that improved social skills are strongly associated with good psychosocial functioning and having confidence, thereby improving quality of life, as well as compensating for cognitive deficits, neurobiological vulnerability, and social maladjustment. In addition, improved social skills compensate for the patient's residual symptoms and deficits in functioning independently. Therefore, PSR that includes social skills training improves support systems which is necessary for improving overall functioning amongst patients with schizophrenia.

Improved problem-solving skills were also reported to help individuals affected by schizophrenia to cope and deal with stressful situations that might exacerbate schizophrenia. This suggests that such skills help individuals to cope with their condition. Previous research has shown that PSR interventions that incorporate social skills training improve treatment adherence and reduce psychiatric symptoms because of the increased support systems and acquired social skills that assist patients to deal with stressful events that can induce relapses (Kopelowicz et al., 2006).

5.3.2. Economic improvement

Economic improvement was a major finding in this study. Participants indicated that they acquired skills which enabled them to budget and engage in income-generating activities. The majority of the participants started small gardens at their home rather than spending their limited grant before the end of the intervention. Others started selling fruits and vegetables, and doing handy jobs. Budgeting was an important skill that was learned whereas some participants reported that they used to spend their money recklessly. However, after

attending the PSR programme they managed to spend money wisely by budgeting and sticking to their budgets. These results are consistent with previous research which suggests that economic improvement skills among patients with schizophrenia are likely to reduce economic stress and improve prognosis (Hudson, 2005). Previous research that reviewed different types of PSR programmes in LMICs highlighted that mental health interventions improve economic outcomes which then improves clinical symptoms, and disrupts the cycle of poverty among individuals suffering from mental illness (Burns & Esterhuizen, 2008).

According to Funk, Drew, and Knapp (2012) poverty has been identified as the root of emotional problems, depression, and severe mental illness. Previous research that documented explanatory models of illness among patients with schizophrenia in the North-West province in South Africa highlighted that participants attributed their illness to poverty and stress (Brooke-Sumner, Lund, & Petersen, 2014). Research postulates poverty may increase risk for schizophrenia. Furthermore, a study conducted in rural and urban KwaZulu-Natal in South Africa highlights that people in impoverished background are likely to suffer from schizophrenia (Burns & Esterhuizen, 2008). It appears that poverty reduces social cohesion and damages social capital, and prolonged stress caused by poverty places human beings at risk of schizophrenia (Burns et al., 2014). Individuals with schizophrenia may lose jobs and drift into poverty, and poverty is likely to aggravate schizophrenia (Funk et al., 2012)

The findings of this study illustrate that economic generation skills should be integrated into PSR programme to reduce economic stress that can worsen schizophrenia and/or leads to rehospitalizations. Rehospitalisation creates a financial burden to the struggling mental health system in developing countries. Therefore, PSR that facilitate economic empowerment is likely to alleviate financial costs to the health system and reduce mental health treatment in LMICs. In addition, Brooke-Sumner et al, (2014) argued that economic improvement activities should be included in the PSR programme for service users with schizophrenia because it promotes recovery and acceptability of the programme.

5.3.3. Reducing risky behaviour

The PSR programme is likely to reduce risky behaviour amongst schizophrenic patients. Several studies show that risk-taking behaviour is very common amongst patients with schizophrenia (Reddy et al., 2014). Therefore, it was not surprising that some of the participants who had attended the PSR programme reported having engaged in risky behaviour. The PSR programme was reported to have assisted in reducing risk-taking behaviour because participants highlighted that they no longer roamed the street at night, and they had ceased smoking and drinking, stopped fighting and engaging in violent behaviour at home, and resisted peer pressure to steal and join bad company.

Several studies have reported a comorbidity of schizophrenia and substance use disorder amongst patients with schizophrenia (Green & Brown, 2006; Thoma & Daum, 2013). It has been observed that schizophrenic patients often use substances because they want to 'get high', wanting to relax, increase pleasure, reduce psychotic symptoms such as hearing voices, and to enable them to socialize (Thoma & Daum, 2013). Substance use amongst patients with schizophrenia is a major public health problem that requires mental health specialists' attention. Research shows that substance use is strongly associated with a higher incidence of unemployment and lower quality of life in schizophrenic patients (Thoma & Daum, 2013).

Prevalence of cannabis use among patients with schizophrenia has been well documented (Koen et al., 2009; Van Os et al., 2010). Cannabis use can exacerbate symptoms of schizophrenia (Thoma & Daum, 2013). Research has shown that cannabis has psychotropic components which increase dopamine activity in the brain (Koen et al., 2009). Cannabis has been reported to elicit relapse and is strongly associated with poor treatment adherence and poorer outcome (Van Os et al., 2010). Consequently, substance use can result in relapse because of non-adherence which will then result in greater health services utilization as a result of the revolving door syndrome.

In addition, violent behavior due to substance use among individuals suffering from schizophrenia may perpetuate public perceptions that schizophrenic patients are violent and aggressive (Thoma & Daum, 2013). Aggression and violent behavior will strengthen stigma

about mental illness. Community-based intervention can be used as a vehicle for changing public perceptions that people with schizophrenia are violent and reduce risky behavior such as substance use, particularly of cannabis. The results of this study show that task-shared community-based rehabilitation has the potential to reduce aggressive behavior and substance use in people with schizophrenia. Similarly, there is growing evidence suggesting that PSR programmes significantly reduce substance use and acting out tendencies in patients suffering from schizophrenia, since they also tend to improve cognitive functioning (Winklbaaur, Ebner, Sachs, Thau & Fischer, 2006).

5.3.4. Treatment adherence

Non-adherence to treatment has been reported globally and it is the most challenging aspect of treating schizophrenic patients. Participants in this study stated that they did not comprehend the importance of treatment compliance prior to attending the PSR programme. This could possibly be the reason why many patients with schizophrenia stop taking their medication after feeling better. Similarly, previous studies exploring factors driving non-adherence to treatment report that lack of insight among patients with schizophrenia is a major contributor to non-adherence (Birnbaum & Sharif, 2008). Lack of insight often leads to absolute denial of the condition and this often leads to complete rejection of treatment. Further, schizophrenia impairs cognitive abilities, which then interferes with the ability to comprehend the importance of taking medication (Birnbaum & Sharif, 2008). Perhaps after feeling better, patients with schizophrenia think that schizophrenia is cured. It appears that the participants diagnosed with schizophrenia did not understand that schizophrenia is a chronic mental illness that requires taking lifelong treatment. However, other reasons for non-adherence reported in the literature include intolerable side effect (Higashi et al., 2010).

Participants who had attended the PSR programme reported that they learned the importance of treatment adherence and the need to take their medication regularly. Similarly, Haddad et al. (2014) argue that community-based rehabilitation improves treatment adherence by 70% because it empowers patients to understand their illness and the importance of treatment adherence. Non-adherence to medication is strongly associated with high rates of relapse, higher incidences of dangerous behaviour, suicide or attempted suicide, arrest, alcohol and drug consumption, poorer prognosis, rehospitalization, loss of

jobs, longer time to remission, psychiatric emergencies, and poor mental performance (Acosta et al., 2012).

Non-adherence to antipsychotic medication can exacerbate schizophrenia and impair functioning, and also create a financial burden to the health system as well as to the family and the affected individuals. Lack of adherence to treatment amongst patients with schizophrenia contributes to the already high costs of schizophrenia to the health system (Lieberman, 2005). Reducing non-adherence to medication through task-shared community-based PSR has the potential to improve the lives of affected individuals and reduce the cost of health care services significantly. This study confirms that community rehabilitation programmes can play a central role in improving adherence and reducing rates of the revolving syndrome.

5.4. Aspect of the PSR that could be improved

This theme addresses the third research question which included exploring parts of the PSR programme that could be improved. However, the majority of participants reported that nothing could be improved. This could be explained by lack of exposure to PSR interventions and lack of sense of agency among patients with schizophrenia. Some participants in the study reported that they could not recall some aspects of the PSR intervention and would respond by saying “I do not know” during the interview. This could be attributed to cognitive decline often associated with schizophrenia (Barlow & Durand, 2015). The cognitive decline might have introduced participants’ bias in the study.

Part of the reason participants reported that nothing could be improved can be explained by power dynamics between field workers and participants, and social desirability which might have led to bias. Research shows that power dynamics between researchers and participants can cause biasness. It appears that power dynamics during data collection can overtly or covertly coerce participants to respond incongruently (Anyan, 2013). Field workers established a trusting relationship with research participants by explaining confidentiality and the use of pseudonyms to protect their identities, and who will have access to the data and how data will be used and stored.

Surprisingly, one participant recommended that the PSR programme should provide additional information about different types of psychological disorders besides schizophrenia. This recommendation clearly shows that some people of SES do not have sufficient knowledge about mental illness and could not easily recognize different types of psychological disorders. This finding is consistent with previous research which reveals that people of lower SES have low levels of mental health literacy (Bruwer et al., 2011). It appears that a majority of people suffering from common psychiatric disorders remain untreated partly because they cannot easily recognize mental illness. Therefore, PSR interventions that will address and psycho-educate about mental illness in South Africa are required as a matter of urgency because research shows that people residing in impoverished areas disproportionately suffer from common psychiatric disorders (Bharathi et al., 2011).

According to Funk, Drew, and Knapp (2012), individuals from the lowest SES are eight times more likely to suffer from schizophrenia when compared to those from the highest SES.

A systematic review exploring the incidence of schizophrenia and income inequality highlighted that people of lower SES are at high risk of schizophrenia (Burns, Tomita, & Kapadia, 2014). It appears that “income inequality impacts negatively on social cohesion, eroding social capital; and that chronic stress associated with living in highly disparate societies places individuals at risk of schizophrenia” (Burns, Tomita, & Kapadia, 2014. P.1). Burns and Esterhuizen (2008) also found an association between lower SES and first episode of schizophrenia in rural and urban areas in KwaZulu-Natal Province in South Africa.

It was unexpected and disturbing to discover that the majority of patients reported that they had not understood the causes and symptoms of schizophrenia before attending the PSR intervention. This finding is, however, consistent with previous research which reveals that a majority of people do not understand common mental disorders including schizophrenia (Farrer, Leach, Griffiths, Christensen & Jorm, 2008). The PSR programme included a session that facilitated understanding schizophrenia. As a result, patients were empowered and understood causes and symptoms of schizophrenia, and they gained a better understanding of their condition. It appears that they felt relieved after gaining knowledge about their condition and discovering that schizophrenia is manageable. This finding signifies that

participants did not have insight into their condition. Research shows that lack of insight is strongly associated with rehospitalisation in LMICs and relapses creates economic burden on the already struggling health care system (Kazadi, Moosa, & Jeenah, 2008). However, improved insight is associated with treatment adherence amongst patients with schizophrenia (Kopelowicz et al., 2006). People of lower SES in South Africa should be empowered with mental literacy through PSR programme to improve their knowledge about mental illness.

Jorm et al. (1997, p. 2) coined the term mental health literacy and defined it as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention”. He further included components of mental health literacy, namely, (a) the ability to recognize specific disorders or different types of psychological distress; (b) knowledge and beliefs about risk factors and causes; (c) knowledge and beliefs about self-help interventions; (d) knowledge and beliefs about professional help available; (e) attitudes which facilitate recognition and appropriate help-seeking; and (f) knowledge of how to seek mental health information. It can be argued that a majority of people cannot easily recognize and distinguish different types of psychological disorders (Jorm et al., 1997

This study suggests a lack of mental health literacy amongst the people of lower socio-economic status (who were the participants in this study) and suggests that psycho-education is helpful for people suffering from schizophrenia. A recent study reveals that psycho-education about schizophrenia promotes mental health literacy in developing countries (Petersen & Lund, 2011), health-seeking behavior, and early intervention, and prevents deterioration of symptoms, thus improving access to mental health care and a better prognosis (Loureiro et al., 2015). Lack of mental health literacy creates a barrier to accessing mental health care services and a recent study suggests that inaccessible and inequitable care and treatment lead to increased mortality and morbidity (Loureiro et al., 2015). Research findings from this study show that mental health literacy can be improved through community-based PSR programmes

5.5. Perception of patients with schizophrenia toward facilitators

Perceptions of patients with schizophrenia toward facilitators address the fourth research question. Few participants had negative perceptions towards facilitators. Participants that had negative perceptions reported that facilitators asked them “difficult questions”. This may suggest cognitive decline in patients with schizophrenia. Patients’ level of cognitive functioning in this study might have introduced participants’ bias and hindered gaining valuable information during data collection. Positive perceptions toward the facilitators might be attributed to social desirability and power dynamics (Anyan, 2013).

The PSR programme was delivered by auxiliary social workers who underwent a five-day training workshop. Facilitators were trained and supervised by a mental health specialist. Facilitators received face to face supervision weekly for the first month of the intervention and then twice a month for the rest of the PSR intervention. PSR facilitators provided support and feedback to each other following each session. Previous studies suggest that training and ongoing supervision of non-specialist health care workers is associated with delivering effective PSR interventions (Mendenhall et al., 2014).

Majority of participants reported that the facilitators were well trained and passionate about their jobs. It emerged that information delivered by facilitators was valuable and beneficial in different ways. Patients with schizophrenia were comfortable with the facilitators and could inform them if they did not understand something. Facilitators asked questions after explaining something to ensure that participants understood what was being discussed. The findings of this study also suggest that the facilitators were confident and organized. It appears that the facilitators of the program provided new experiences of being accepted and understood without being judged. Experiences of being heard and understood validated the participants’ experiences that had been invalidated by family and community members. Therefore, these findings suggest that task-sharing of PSR as a mechanism for delivery of such interventions in the context of a shortage of specialists is acceptable to service users with schizophrenia.

This finding is consistent with previous research studies suggesting the effectiveness of task-shared community-based interventions for patients with schizophrenia in developing countries (Botha et al., 2010; Chatterjee et al., 2003; Chien et al., 2013). It must be noted that few studies have reported the effectiveness of task-shared interventions for schizophrenia in developing countries. Therefore, this study contributes to the body of growing evidence showing the effectiveness of task-sharing in improving treatment compliance, enhancing social skills, and reducing stigma. However, the task-shared community intervention will only be effective if facilitators are well trained and appropriately compensated.

5.6. Family and community changes

Five sessions with caregivers which facilitated understanding of schizophrenia and reducing stigma were included in the PSR intervention. This theme addresses the fifth research question which explored how the intervention helped the family and community to understand schizophrenia. Sub-themes generated from this overarching theme included improved understanding of schizophrenia amongst family and community members, reducing stigma, social inclusion and personal hygiene.

5.6.1. Improved understanding of schizophrenia amongst family and community members.

Schizophrenia is a debilitating and chronic mental illness that causes emotional and financial burdens to the supporting family members. Schizophrenia also causes disruption of family interaction and activities, and distress for the caregivers of affected individuals. A study conducted among Xhosa people in South Africa highlights that families tend to view patients with schizophrenia as dangerous and dirty (Asmal, et al., 2011). This paper argues that such view will weaken support system for patients with schizophrenia and cause emotional problems to the affected individuals. Secondly, this shows that families do not understand schizophrenia. According to Acosta et al. (2012), lack of family and community support contributes to high rates of relapse and readmission. Families and communities often do not understand schizophrenia and have difficulties caring and coping with someone diagnosed with schizophrenia. In the last few decades, research studies show that high-functioning

families promote speedy recovery, treatment adherence, and improved quality of life (Acosta, et al., 2012). Asmal, et al. (2011), argues that family interventions that educate families about schizophrenia improves support system for patients with schizophrenia, reduces risk of relapse, improves treatment adherence and family burden. Research shows that family interventions for schizophrenia have been found to be effective in reducing emotional difficulties in relatives, revolving door syndrome, and improving social functioning in Iran (Koolae & Etemadi, 2010), in India (Kulhara, Chakrabarti, Avasthi, Sharma, & Sharma, 2009), and in Pakistan (Nasr & Kausar, 2009). It appears that family interventions for schizophrenia are likely to reduce emotional problems to the caregivers and financial burden to the already struggling health care system in LMICs. Therefore, there is a need for more studies on PSR that incorporate families of affected individuals in LMICs.

Participants in this study indicated that the PSR programme empowered their family and community members with a better understanding of schizophrenia. As a result, there was a change in how patients were treated by family and community members. Patients indicated that family and community members ceased to ridicule them and to say they were useless. This shows that patients with schizophrenia were no longer treated like mad or crazy persons, but community and family understood their condition and learned to treat them like normal human beings. It also appears that the community realized through PSR that persons with schizophrenia have feelings and get hurt when mistreated.

Participants also indicated that their family and community members were better informed about schizophrenia as a chronic illness and understood that the prognosis was poor if a patient did not adhere to treatment. Furthermore, families of service users learned that schizophrenia is manageable, like diabetes and high blood pressure. Research findings of this study illustrate that PSR interventions that incorporate families and communities play a central role in addressing non-adherence amongst schizophrenic patients as they can assist in providing patients with the necessary support to adhere. The findings are consistent with previous evaluation studies which suggest that interventions that include family members improve adherence by 70% (Haddad et al., 2014), and family interventions that encourage patients with schizophrenia to have ongoing contact with their family members and

communities also tend to increase adherence to medication and reduce psychotic symptoms (Kreyenbuhl et al., 2010).

Lack of family and community support increases incidences of non-adherence; for example, some patients with schizophrenia live alone which increases the risk of not taking prescribed medication (Acosta et al., 2012). Recent research shows lack of family and community support system is strongly associated with high rates of non-compliance (Acosta et al., 2012). Therefore, community-based PSR for patients with schizophrenia should endeavour to include family members to increase adherence to treatment and improve the quality of life and strengthen support systems for patients with schizophrenia. The strong support system will also help patients with schizophrenia to cope with their disorder. This idea is supported by a meta-analysis study which highlighted that family interventions prevent relapse, readmission, and improve compliance with medication amongst patients with schizophrenia in LMIC (Pilling et al., 2002). This suggests a growing body of evidence on the efficiency of family interventions in improving the quality of life, improving treatment compliance, and reducing the revolving door syndrome.

5.6.2. PSR programme can reduce stigma

Another challenge facing patients with schizophrenia is that they are perceived as dangerous, irresponsible, and unpredictable. However, it appears that PSR programme has a role to play in reducing the stigma of mental illness. This was confirmed in this study because participants reported that they felt understood and free to disclose their illness to the community. Evidently, through the PSR programme, people in the community understood schizophrenia better and started to socialize with schizophrenic patients. Socializing with patients suggests that the PSR programme managed to change public perceptions that patients with schizophrenia are dangerous, violent, aggressive, and irresponsible.

As suggested above, family and community interventions should be incorporated into PSR programmes delivered to patients with schizophrenia. This is especially important because stigma represents a major challenge concerning the integration of persons with schizophrenia into the community. Stigma normally creates a barrier to access to mental health services and

it leads to poor prognosis and damages self-esteem. Van Zelst (2009, p. 1) argues that “stigmatization represents a chronic stressor and therefore, given evidence that stress triggers episodes of schizophrenia, may act as a modifier of illness course”. Previous research indicate that stigma as a social stressor aggravates psychotic symptoms and causes clinically significant distress in social functioning. Furthermore, social disapproval, discrimination, and low self-esteem due to mental illness stigma have been major factors causing poor adherence to treatment (van Zelst, 2009).

Research shows that psychological outcomes of stigma include depression, guilt, withdrawal, anxiety, anger, fear, and embarrassment (Dinos, Stevens, Serfaty, Weich & King, 2004). Patients with schizophrenia are at high risk of being diagnosed with social anxiety disorder due to the feelings of shame associated with a schizophrenia diagnosis (van Zelst, 2009). Therefore, PSR for patients with schizophrenia that includes families should be implemented in developing countries to address stigma and reduce the negative psychological consequences resulting from stigma which leads to poor prognosis and low quality of life. Previous studies on family interventions report reductions in the stigma surrounding mental illness (Pilling et al., 2002).

Part of this study was to explore the acceptability of the PSR programme in the community. The findings clearly show that the program was well accepted since there was an improvement in how family and community members treated persons with schizophrenia. Acceptability of the program is revealed by a decrease of the stigma surrounding schizophrenia and inclusion of patients with schizophrenia in family and community activities.

5.6.3. Roles and activities

Patients with schizophrenia often experience exclusion from partaking in community and family activities (van Zelst, 2009). Participants in this study highlighted that, after the PSR programme, they were able and allowed to engage in family and community activities. The majority of participants reported that they had started washing their clothes, dishes, and cooking. In addition, some individuals managed to get temporary jobs such as packing boxes at the school, doing handy jobs, and one participant started learning to weld and to work with

metal. This suggests improvements in occupational and social functioning, and this also has the potential to reduce economic stress.

It appears that an inability to contribute to household activities causes stress, reduces self-esteem, and makes patients feel like they are useless and not needed in their household and community. Van Zelst (2009) argues that improving household contributions has the potential to reduce the burden to the family members and increase the patient's self-esteem. Therefore, PSR should also focus on improving and encouraging patients with schizophrenia to have responsibilities and roles in their family and community. Furthermore, PSR programmes that incorporate family members should emphasize inclusion of persons with schizophrenia in family and community activities. Research findings in this study clearly reflect the value of community-based PSR programmes in encouraging and improving patients' contribution to family and community activities.

5.6.4. Personal hygiene

The findings of this study suggest that community-based rehabilitation also has the potential to improve personal hygiene as participants in the study reported improvement in personal hygiene after attending the PSR intervention. Prior to joining the intervention, some participants reported that they could not wash themselves, their clothes, dishes, etc. PSR programmes improve cognitive and social functioning (Chien et al., 2013). Poor personal hygiene also makes it difficult for family and community members to socialize with individuals suffering from schizophrenia and so improved personal hygiene has the knock-on effect of improving social interaction. It appears that lack of personal hygiene amongst schizophrenic patients is attributable to apathy and lack of motivation, and poor insight and judgment. Individuals with schizophrenia do not recognize the impact of bad body scent on others. Poor personal hygiene is a serious issue that needs to be addressed through community-based PSR because if overlooked, it will perpetuate the stigma of mental illness.

5.7. PSR as a good way to supporting people with schizophrenia

Participants indicated that the community-based PSR programme was helpful in supporting individuals suffering from schizophrenia. In particular, providing impetus for generating an income and obtaining information about schizophrenia emerged as the main reasons for suggesting that the PSR programme was helpful. Part of the study included exploring if participants would recommend the PSR programme to other people in their community. All participants reported that they would recommend the PSR programme to other community and family members diagnosed with schizophrenia. Similarly, previous studies on effective treatments for schizophrenia recommended a combination of psychotropic medication and task-shared PSR programmes, since single therapeutic approaches are generally inadequate and ineffective, while a combination of both approaches improves prognosis and recovery (Botha et al., 2010; Chien et al., 2013; Lemmi et al., 2016). Moreover, PSR programmes have been recommended because they are cost effective and effective in reducing symptoms (Pilling et al., 2002).

It emerged that participants would recommend the PSR programme because other people suffering from schizophrenia need to understand their illness and the importance of adhering to treatment. This demonstrates the importance of mental health literacy and that people do not understand the importance of treatment adherence. Lack of mental literacy and understanding the value of treatment compliance explains the high rates of the revolving door syndrome. Furthermore, the findings illustrate the positive impact the PSR programme had on the patients with schizophrenia and the importance of promoting mental health literacy.

5.8. Conclusion

This chapter presented explanation and interpretation of research findings. Research findings in this chapter suggest that task-shared community-based PSR programme can play a crucial role in addressing a shortage of mental health professionals and reducing a 75% treatment gap for common mental disorders in South Africa. Participants in this study had a positive experience of the program and the gained insight into their condition which is essential for treatment adherence and reducing revolving door syndrome. The PSR programme facilitated understanding the importance of treatment compliance among patients with schizophrenia.

The PSR programme played a pivotal role in reducing risky-taking behavior, improving socializing skills and personal hygiene amongst patients with schizophrenia. This chapter indicated that task-shared intervention has a potential to improve occupational functioning thus reducing economic stress which might exacerbate schizophrenia. It appears that task shared intervention can reduce stigma about mental illness and equip patients with schizophrenia with necessary coping skills that will assist them to deal stigma. The inclusion of families and community in PSR programme is likely to promote social inclusion in family and community activities which will then improve self-esteem of the affected individuals. This chapter emphasized that some people of SES lack knowledge about mental illness and some people remain untreated because they cannot recognize mental illness. Therefore, task-shared interventions that will psychoeducation people of low SES about mental illness are needed in South Africa. This section suggested that community-based PSR is a good way to support patients with schizophrenia. Therefore, South Africa should endeavor to implement more PSR programmes for individuals suffering from schizophrenia.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

As indicated previously, decentralization of mental health services in South Africa has not been accompanied by sufficient community-based rehabilitation programmes. Community-based PSR programmes could potentially assist to improve human rights of mental health care users through reducing reliance on custodial /institutional care that has been associated with human rights abuses (Chow & Priebe, 2013; Patel, 2007). Decentralized mental health services need to be accompanied by PSR programmes for deinstitutionalization to be successful. Deinstitutionalization of psychiatric patients back to their communities without adequate PSR interventions is irresponsible the revolving door phenomenon (Petersen & Lund, 2011), and this creates a financial burden to the already struggling health system in South Africa.

The aim of this study was to conduct a process evaluation of a decentralized community-based PSR programmes for patients with schizophrenia delivered by ASW in DKK district, North West province. The findings of this study suggest that community-based PSR for individuals suffering from schizophrenia can help sufferers to cope better with the disorder, reduce the revolving door syndrome, improve patients' quality of life, social skills, and family and community support. It can be inferred from the research findings of this study that community-based PSR has a potential to help patients with schizophrenia and their families to cope with their diagnosis.

An important finding that was unexpected from this study was that some patients with schizophrenia did not understand the symptoms and causes of schizophrenia. This suggests a lack of mental health literacy amongst people of low socio-economic status. Lack of mental health literacy amongst this population group indicates that there are many people who might be suffering from mental illness which remain untreated. Therefore, community-based interventions aimed at improving mental health literacy can help increase access to mental health care services because the lack of mental health literacy is a barrier to access to health care. Similarly, Patel (2007) argued that PSR programmes are needed to increase mental health literacy in LMICs.

In the context of a shortage of mental health specialists, this study suggests that the task-sharing approach can help reduce the 75% treatment gap for common psychological disorders in South Africa. This is consistent with previous studies that suggest that task-sharing is a strategy that can be adopted to compensate for the shortage of mental health specialists in LMICs including South Africa (WHO, 2008). This study indicates that task-sharing is likely to be effective when facilitators are well trained, supported, and supervised. Similarly, several studies have indicated that proper training and supervision of facilitators can result in effective PSR programmes, whereas a lack of supervision and training is strongly associated with ineffective interventions (Mendenhall et al., 2014).

Community-based PSR interventions that include families and communities are necessary because patients who receive strong family support tend to have greater adherence to treatment and experience lower rates of relapse. An intervention that includes families can potentially play a central role in reducing the financial burden on the health system caused by readmission in psychiatric hospitals. In addition, these interventions have been found effective in assisting family members to cope with and take care of individuals suffering from schizophrenia. Controlled studies highlight that family interventions improve family support systems that help patients deal with stressful situations that might exacerbate their condition (Iemmi et al., 2016). The findings of this study also suggest that community-based PSR can help to reduce mental illness stigma. A PSR programme that encourages the inclusion of patients with schizophrenia in community activities reduces the family burden caused by a lack of household participation and stigma. The inclusion of patients with schizophrenia in household and community activities will also help to boost self-esteem and reduce feelings of shame which could possibly lead to a comorbid diagnosis of social anxiety disorder.

Developing countries should try to design and implement community-based PSR because these interventions are potentially cost effective as well as having the potential to reduce relapse and readmission which are more costly. Developing countries should refrain from institutionalization of psychiatric patients because mental hospitals have been severely criticized for violation of human rights and poor living conditions (Chow & Priebe, 2013).

Goffman (1961) argued that institutionalized psychiatric patients experience mortification of the self and that psychiatric hospitals create closed systems that separate patients from their communities; as result, they have limited access to the outside world. In addition, a study exploring the impact of a prolonged stay in psychiatric hospitals reveals that poor living conditions exacerbate psychiatric symptoms (Breakey, 1996).

6.2 Limitations of the study

Although rich data emerged from this study, like any other research project this study also has limitations.

1. This study had a relatively small sample and is therefore not generalizable.
2. It was difficult to get detailed responses from some service users because of their level of cognitive functioning. This might have hindered obtaining rich data from the participants.
3. All the participants had positive perceptions of facilitators and reported that nothing could be improved in the study. This can raise concerns about bias in the study as a result of social desirability and unequal power relations between the participant and the interviewer.

6.3 Recommendations for future interventions

Firstly, decentralization of pharmacological treatment of patients with schizophrenia and other psychotic disorders should be accompanied by community-based PSR programmes to improve their prognosis, to reduce the revolving door syndrome, improve the quality of life, and help facilitate the reintegration of service users back into their community.

Secondly, there is a need for community-based mental health literacy programmes especially for people of low socio-economic status. This should promote better understanding of people suffering from mental disorders within the community and assist to reduce stigma, and promote acceptance and reintegration into community life and activities.

Thirdly, task-sharing should be embraced for the development of community-based PSR programmes in the context of the shortage of mental health specialists in South Africa.

However, facilitators delivering task-shared interventions need proper training and supervision to provide effective PSR interventions.

Fourthly, community-based PSR interventions should incorporate family interventions that will assist family members to cope and deal with the affected individual. Such PSR programmes will strengthen the family support system which then should assist to promote recovery, increase adherence to treatment, and reduce the high rates of relapse amongst patients with schizophrenia.

6.4 Recommendations for future research

1. Since there is limited evidence of community-based PSR for schizophrenia in South Africa, more studies should be implemented and evaluated to generate evidence-based interventions for schizophrenia.
2. Further rigorous assessment of this intervention, using a randomized control trial design with objective measures of improvement in functioning is recommended.

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APPENDICES

Appendix A: interview guide

Understanding the impacts of participation in group counselling sessions with collective mobilisation modification (Schizophrenia/depression groups)

Service user/patient interview schedule

Section 1: Life history and background section

Note to interviewer: The aim of this section is to develop a life history of the participant. Please use only relevant questions as part of this process.

Interviewer introduction: We're going to start off today by getting to know a bit about your life, and your family, to ask you a couple of questions:

Where were you born?

Do you have any brothers and sisters? where are they now? do you see them often?

Can you tell me a little about your parents? where are they now? If deceased how did they die? how did that feel?

Can you tell me about a happy story from when you were a child?

Did you go to school? For how long? why did you stop going?

How long have you lived in this house?

Are you married? how long have you been married? is it a happy marriage?

Do you have any children? How many children do you have? how old are they? are they in school?

What are the two hardest things about your life right now?

What are the two best things about your life right now?

Can you tell me a story that would describe what a typical day is like for you?

Section 2: Discussion of mental health history

Interviewer introduction: As you know, this study is about trying to understand your experiences in managing your schizophrenia, and how your recent participation in the group counselling intervention has helped that. The following questions will help to explore this a bit more.

1. Can you explain to me when you first realised that you may have schizophrenia?
 - a. Probe for previous experiences of distress, involvement of family or friends or community members
2. How did you feel when you were told about your diagnosis of schizophrenia?
 - a. Probe for feelings of fear, concern about family, if not stated

3. What do you understand your diagnosis of schizophrenia to be?
4. What symptoms do you have?
5. How do these symptoms affect your life? (Probe for the problems they have caused for the participant).
6. What do you think caused your schizophrenia?
7. What medication do you take for your schizophrenia?
Probe: Name? Tablet/injection
8. What directions do you have from the doctor on how to take your medication?
Probe: Do you follow these?
9. What side effects does your medication have?
Probe: Do you know how to deal with these?
10. Have you been taking your medication for your illness regularly over the past 3 months?
 - If yes – what helps you to take your treatment regularly? Have you noticed a difference since being part of the support group?
 - If no – What prevents you from taking your treatment? What would help you take your treatment regularly in the future?
11. Have you had a relapse of your illness which has made it necessary for you to go into hospital in the past 3 months?
 - If yes – how many relapses? What do you believe caused the relapses?
 - If no – when was the last time you were in hospital, if ever? What has prevented you from needing to be hospitalised?
12. Have you had problems with alcohol and substance abuse since being in the group?
13. Have you had an encounter with law enforcement since being part of the group?
 - If yes – please explain the situation and what happened.
 - If this has happened more than once, how many times has it happened?
14. How did you come into contact with mental health services at your local clinic?
15. Can you tell me what your intervention was like?
 - a. Probe for – type of intervention,
 - b. who was involved in your intervention?
 - c. what did you learn?

Experience with intervention

16. How did you experience the intervention?
Do you feel comfortable being involved in the group?

Why/Why not?

Prompting questions:

17. Did participation in the counselling programme change the way you think and feel about yourself?
 - *If yes, probe for how.*

- *Ask participants to describe the way the programme has changed the way they think, feel and behave after participating in the programme compared with before the programme.*

18. Did participation in the counselling programme change the way you think, feel about others and the way you relate to others?

- *If yes, probe for how.*
- *Ask participants to describe the way they think and feel about other people and their relationships now after participating in the programme compared with how they felt about other people/their relationships before the intervention.*

19. Did counselling help you deal better with situations that were troubling you?

- If yes, probe for how.*
- If no, probe for why.*
- Ask participants to provide an example of a time when they used what they learned in their counselling session*

20. Do you think your being part of this group has helped people in your family and community understand you and your illness?

Prompt:

- Why or Why not?
- Has this changed the way they treat you? If so, how?

21. Are there any roles in your family or community that you now able to carry out that you could not before?

Prompt:

- Roles in family e.g. childcare
- Roles in community e.g. community leader
- Roles at Work
- Roles in the Household e.g. cooking, cleaning
- Roles in church or other community organisation
- What about this/these role/s is important to you

22. Can you describe what your group usually did when you met?

Prompt:

- Education on illness and treatment?
- Income generating activities?

23. Can you describe the role of the facilitator in the group? Has the information given to you by the facilitator been helpful?

If yes:

- What has been the most useful information and why?
- What additional information would have been helpful?

If no:

- What information would you have liked for the facilitator to give?

Was information presented to you in a way that was easy to understand and apply to your life?

Probe:

- Can you give an example of something you learned in the group and then applied to your life

24. Did the facilitator seem confident and organized?

Probe: Why or Why not?

25. Did the facilitator refer you to another service provider for help/support if you needed it?

If yes: Please can you describe where you were referred and why.

- What information did they provide?
- What support did they give?
-

26. What motivated you to join the group?

Probe:

- What motivated you to keep coming to group meetings?
- What discouraged you from coming to group meetings?
-

27. Has your group stayed active over the past weeks?

Which session(s) did you find most useful?

- Probe for in what ways they were useful.*
- Ask for examples.*

28. Which parts of the programme were not useful to you?

- *Probe for why these aspects were not useful.*

29. Did the counselling help with:

- *Personal problems? Probe for how.*
- *Other ways e.g., income generation, interpersonal relationships etc? Probe for other ways that it was helpful.*

30. Do you think your being part of this group has helped people in your family and community understand you and your illness?

Prompt:

- Why or Why not?
- Has this changed the way they treat you? If so, how?

31. Do you feel excluded from social activities that your family or community participate in? Has this changed since being part of the support group?

Prompt:

- What social activities do you now participate in?

32. Have you made new friendships through being part of the support group?

Prompt:

- If yes, How has this affected your life?
- If no, What makes it hard to build friendships?

33. Have you received your disability grant over the past 3 months?

- If yes – what do you use the grant for? Has this changed since you have been part of the support group?
- If no – do you know that people with psychiatric disability are eligible for government grants? Do you know where to go to access these grants?

34. Does your caregiver manage your grant money or do you do this yourself? Has this changed since being part of the support group?

35. How do family members treat you?

Prompt:

- Do you feel your family understand your illness?
- Are they supportive?

Skills and Goal Setting

36. Have you gained any skills since being part of the support group?

- If yes, please describe these skills and how they have affected your life.

36. Has the support group has helped you to set goals and work towards these?

Prompt:

- What goals have you set? Have you made progress towards achieving these goals?

37. What aspects of the programme would you say did not work well?

- *Probe for what they think made these not work well.*
- *If these were to be changed, how would you change these?*

38. Were you comfortable with the way counselling intervention/ group counselling was carried out?

39. One of the sessions you completed gave you the opportunity to work as a group to tackle a problem that was linked to your condition. Can you tell me how that worked?

- a. Probe for: what they chose to do for their group action
- b. What went well with that collective action
- c. What didn't work well?
- d. What would you change about that session?

40. Were you comfortable sharing your opinions, feelings, and thoughts in the group?

- *Probe for whether the group meetings were organised and carried in an appropriate manner.*
- *Probe for whether they got all the attention they needed in the group.*

41. Were you comfortable speaking to the counsellors?

42. From your experience of the counselling, do you think the counsellors were adequately trained for their job?

- *Probe for any difficulties with the facilitators.*

43. Are there aspects that you feel could be improved?

- *If yes, probe what aspects?*
- *How could these be improved?*

44. How would you rate how you feel now, compared to how you felt before participation in the group?

Probe for Symptoms

- *Feeling worse.*
- *Unsure/ don't know.*
- *Feeling the same.*
- *Feeling a lot better.*
- *Why?*

45. How have the group sessions changed your life?

- Probe for differences in how they interact with their family, wider community,
- Ability to carry out tasks eg Are some tasks easier after participation in the group

46. A support group is one way of supporting people with schizophrenia, do you think it is a good way?

If yes:

- What benefits have you seen for yourself and others in the group?
- What do you enjoy about the group?

If no:

- What other way do you think would be better to support people with schizophrenia, and why?

47. Are you able to get to the group meetings easily?

Are the group meetings held in an appropriate and easily accessible venue?

Has the group gained acceptance in your community?

- If yes: Please describe why you think this has happened.
- If no: Please describe why you think this has not happened.

48. Would you recommend this programme to another person? Why?

49. What, if anything, would you like to change about the support group?

Prompt:

- What would you change about how the group is run?
- What would you change about the activities you do?
- What would you change about who is involved in the group?
- Would you change the venue where the group meets?

50. Are there any issues we have not adequately covered in this interview

51. Is this support group something that you would like to continue to be involved in?

Appendix B: informed consent

PRIME-SA: PRogramme for Improving Mental Health CarE in South Africa. Cohort Study

Study Information Sheet and Consent for Service Users: Process evaluation for psychosocial group rehabilitation for schizophrenia

To participate in a study to assess the outcomes of integrated mental health care

You will be given a copy of this information sheet

The Project: PRIME-SA: PRogramme for Improving Mental Health CarE in South Africa. Cohort Study

Date:

Dear Service User,

I am a researcher working with the PRIME (Programme for Improving Mental Health Care) project at the University of KwaZulu-Natal in Durban, South Africa. The Principal Investigator of this project is Professor Inge Petersen. She is based at UKZN in Durban. The PRIME-SA project including the current study is funded by the Department of International Development (DFID) in the United Kingdom.

You are invited to participate in a study that involves research about integrating mental health care into the chronic care provided at your primary health care clinic. Before agreeing to take part in this research study, please read the information below so that you understand what the study will involve. Please read this carefully and feel free to ask me if there is anything that is not clear or if you have any questions about your participation. We are asking you to participate in a study to provide information on the outcomes for patients treated for psychosis at primary health care level.

What is the purpose of this study?

The aim of the study is to gather information about whether treatments for schizophrenia provided at this clinic are helpful to patients. We would like to find out about the outcomes of these services on patients' health. We would like to know if the service that you received, specifically the group psychosocial rehabilitation was useful to you. We would like to know how you experienced the group sessions, whether they were of any benefit to you and what feedback you can give us to improve the group psychosocial rehabilitation programme for schizophrenia.

Who are we asking to participate?

We are asking all patients aged 18 years and older who have been diagnosed with schizophrenia, attending clinics and the group psychosocial rehabilitation for schizophrenia programme in the Dr Kenneth Kaunda District to participate. The study will be conducted from July 2014 to July 2016. We would like to interview patients from the three clinics in this research study who have participated in the group rehabilitation study.

What will it mean if you participate in the study?

If you agree to participate in the study, you will be interviewed by me. The interview will take approximately 60 minutes. During the interview, you will be asked a number of questions about your mental health and your use and experience of the health services at this clinic. I would also like to look at the consultation notes in your clinic file, today if you agree to this.

Will my information remain confidential?

Yes. Should you agree to take part in the study, all your records will be seen by the study researchers only. Information and results of the study that are shared with other researchers will not contain any identifiable (personal) information such as names or contact details. Every effort will be made to keep your information confidential. Although we will try to conduct this interview in a private room, it might happen that, during the course of your interview, another patient or clinic staff member comes into the room. Should this happen I will pause the interview when another person has entered the room, unless it is another member of the research team, such as my supervisor). However, if you express thoughts of suicide or intention to harm yourself or others, I will have to refer you to the clinic. In this case I will coordinate with my supervisor to immediately refer you to the clinic or to Dr Von Wiellig, the psychologist at the clinic .

The possibility also exists that, despite the absence of identifying data, the clinic could be identified as one of the research sites due to a process of deduction from the public information about the PRIME project. This does not mean that you yourself will be identified but that the aggregate data from the study may be linked back to your clinic.

No personal identifying details will be recorded from your clinic file notes. This information will only be used to see what happens in your consultation with the nurse today. The information from your interview as well as your clinic consultation will be stored on a computer and protected with a password. Your data will be stored under password protection for up to five years on the PRIME-SA computers.

What are the possible benefits of participating in this study?

You will be asked to give approximately 60 minutes of your time to participate in this interview. You will receive a R30 voucher for your time.

What are the possible drawbacks or discomforts of participating in this study?

If you agree to participate in this study, you will be asked a number of questions about your illness (schizophrenia) and your experience of participating in the schizophrenia group rehabilitation programme, in an interview that should take approximately 60 minutes of your time. Some of these questions about your condition might be of a sensitive nature. If you experience any discomfort or distress during the course of this interview, related to your condition you will be referred to Dr J Von Wiellig (primary health care psychologist serving the sub-district) to help you with your condition/concerns. Dr Von Wiellig may be contacted on the following number: 018 464 2210 (extension 107)

Do I have to participate in this study?

It is your choice whether you want to participate in this study or not. If you decide not to participate, you will not be prejudiced in any way, and your decision will not affect the treatment you receive at your clinic. If you decide to take part, you are still free to withdraw from the study at any time and without giving a reason. Should you decide not to take part, or if you withdraw from the study, this will in no way affect the care you receive at the clinic. Should you agree to participate, we will ask you to sign the attached consent form.

Use of information from this study

We will use this information from the current study to evaluate the programme from the perspective of service users ie. what service users think about the programme and how they experience the programme. If you agree that we may use this information for future research we will only use it once we have received ethical permission to use this data in the new study.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number BE258/14).

| For questions related to the study | For Your rights as a research participant |
|---|--|
| The Principal Investigator, Professor Inge Petersen Department of Psychology Howard College Privat Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 260 7970 Email: Peterseni@ukzn.ac.za | BIOMEDICAL RESEARCH ETHICS COMMITTEE Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 2604769 - Fax: 27 31 2604609 Email: BREC@ukzn.ac.za |

Consent form for service users' participation in the study to conduct the PRIME-SA Cohort Study

Please complete this form after you have been through the information sheet and understand what your participation in this study entails.

Thank you for considering taking part in this study. If you have any questions arising from the information sheet, please ask before you decide whether to take part. You will be given a copy of the information sheet and consent form.

I, (write your name here), _____ have been informed about the evaluation of the PRIME-SA Cohort Study.

I understand the purpose and procedures of the study.

I have been given an opportunity to ask questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

if I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact

| For questions related to the study | For Your rights as a research participant |
|--|---|
| <p>The Principal Investigator, Professor Inge Petersen Department of Psychology Howard College Privat Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 260 7970 Email: Peterseni@ukzn.ac.za</p> | <p>BIOMEDICAL RESEARCH ETHICS COMMITTEE Research Office, Westville Campus Govan Mbeki Building Private Bag X 54001 Durban 4000 KwaZulu-Natal, SOUTH AFRICA Tel: 27 31 2604769 - Fax: 27 31 2604609 Email: BREC@ukzn.ac.za</p> |

| | |
|--|------------------------|
| | Please tick or initial |
|--|------------------------|

| | |
|---|--------------------------|
| I understand that if I decide at any time during the study that I no longer want to take part, I can notify the researchers and withdraw without having to give a reason. | <input type="checkbox"/> |
| I consent to the clinic consultation notes from my patient file being reviewed. | <input type="checkbox"/> |
| I consent to the processing of my personal information for the purposes explained to me. | <input type="checkbox"/> |
| If my data is to be used for future research, I agree that this can be used on condition that ethical approval has been obtained, and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. In such cases, as with this project, data would not be identifiable in any report. | <input type="checkbox"/> |

Signature of Participant

Date

Signature of Witness

Date(Where applicable)

Signature of Translator

Dat(Where applicable)

Appendix C: PRIME project Ethical Clearance



UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

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Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

Amended letter

10 December 2015

Prof I Petersen
Department of Psychology
Howard College
UKZN
Durban
4041
Peterseni@ukzn.ac.za

Dear Prof Petersen

PROTOCOL: Strengthening mental care in chronic care patients with Hypertension. A cluster randomised trial: Non-Degree: Psychology. BREC REF: BFC049/15

We wish to advise you that your correspondence dated 02 November 2015 requesting approval of Amendments (to conduct fidelity checks to assess the psychosocial intervention sessions conducted by the lay counsellors and aid supervision) for the above-mentioned study has been noted and **provisionally approved** by a sub-committee of the Biomedical Research Ethics Committee subject to the submission and approval of the isiZulu translations and back translations by BREC.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Mrs A Marimuthu'.

Mrs A Marimuthu
Senior Administrator: Biomedical Research Ethics