

https://dspace.org/

Perceptions of mental health care users diagnosed with major depressive disorder of factors that lead to readmission

Roestorff-Hambrock, Nadia

2018
https://hdl.handle.net/10539/25287

Downloaded from a DSpace repository. https://dspace.org/

PERCEPTIONS OF MENTAL HEALTH CARE USERS DIAGNOSED WITH MAJOR DEPRESSIVE DISORDER OF FACTORS THAT LEAD TO READMISSION

Nadia Roestorff-Hambrock

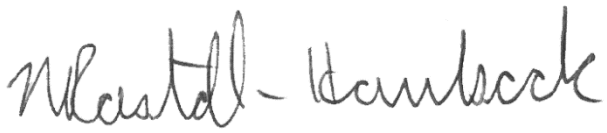
A dissertation submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Master of Science in Occupational Therapy

Johannesburg, 2017

DECLARATION

I, Nadia Roestorff-Hambrock declare that this dissertation is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy to the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signed:



6th day of November 2017

DEDICATION

To my parents, Ernst and Titia Roestorff, for having always been my anchor and my wings.

ABSTRACT

Major Depressive Disorder tends to have a chronic course and Mental Health Care Users with this diagnosis experience challenges after discharge that impact recovery.

A qualitative approach and descriptive design were used to explore these challenges and the perceived value that mental health care users attach to support group attendance after discharge. Data were gathered through semi-structured interviews with eleven participants. The transcribed interviews were analysed thematically. Data analysis generated four themes: “Inability to fully benefit from hospitalisation”, “Life was not what I expected it to be after discharge”, “I did not feel supported after discharge” and “Support groups could be valuable”.

This study showed that learning is compromised during the acute phase of the disorder affecting the implementation of coping skills after discharge, that recovery is a journey that extends beyond hospitalisation, that the experience of isolation after discharge is detrimental to recovery and that support groups could compensate for some unmet treatment needs at discharge.

Keywords: Major Depressive Disorder, challenges, readmission, occupational therapy

ACKNOWLEDGEMENTS

To my supervisors, Prof Pat de Witt and Dr Fasloen Adams: Thank you for your continued support, helpful feedback and patience in allowing me the opportunity to finish this dissertation.

To my husband Thomas: Thank you for countless hugs and cups of tea, for late-night walks around the block to clear my head and for telling me to get back to the computer when I did not want to write anymore. With the completion of this study, we can truly say: onwards and upwards to new adventures!

To my parents, Ernst and Titia Roestorff: Thank you for your continued encouragement and belief in me. How can I ever thank you enough. Your approach to life is inspirational.

To my aunt Mandie and friends Helene, Lizelle and Lorinda: Thank you for keeping me in your prayers.

To the participants in this study: Thank you for willingness to share your experiences with me.

To the management of the Private Psychiatric Hospital where this research was conducted: Thank you for allowing me to carry out this study.

Above all: Thank you Lord.

"U redde mij en riep mijn naam. Gaf mij weer hoop, een nieuw bestaan." – *Opwekking 578, Nederlands zangbundel.*

TABLE OF CONTENTS

DEDICATION iii

ABSTRACT iv

ACKNOWLEDGEMENTS v

TABLE OF CONTENTS vi

LIST OF TABLES xii

LIST OF FIGURES xiii

DEFINITION OF TERMS xiv

ABBREVIATIONS xvi

CHAPTER 1 1

INTRODUCTION 1

1.1 Introduction 1

1.2 Background to the study 1

1.3 Problem statement 4

1.4 Research questions 5

1.5 Aim of the study 5

1.6 Objectives of the study 5

1.7 Justification of the study 5

1.8 Outline of the study 6

CHAPTER 2 7

LITERATURE REVIEW 7

2.1 Introduction 7

2.2 Symptoms of Major Depressive Disorder 7

2.3 The course of Major Depressive Disorder 8

2.4 Theories and models for recurrence of Major Depressive Disorder 9

2.5 The implications of relapse and readmission 10

2.6 Risk factors for the recurrence of Major Depressive Disorder 11

2.6.1 Clinical risk factors associated with the recurrence of Major Depressive Disorder 11
2.6.1.1 Course and impact of MDD episodes 12
2.6.1.2 Personal attributes 13
2.6.1.3 Psycho-social factors 14
2.6.2 Perspectives of Mental Health Care Users 15
2.6.2.1 Causal factors that MHCUs attribute their MDD to 16
2.6.2.2 The lived experience of recurrent MDD 18
2.6.2.3 Post-discharge challenges 19
2.7 Recovery from Major Depressive Disorder 20
2.8 The role of support in the recovery from Major Depressive Disorder 22
2.8.1 Informal support 22
2.8.2 Structured support 25
2.8.3 Transitional discharge 25
2.9 Conclusion 26
CHAPTER 3 27
METHODOLOGY 27
3.1 Introduction 27
3.2 Research approach and design 27
3.2.1 Worldview 27
3.2.2 Research approach 28
3.2.3 Research design 28
3.2.4 Research setting 29
3.3 Sampling 29
3.3.1 Study population 29
3.3.2 Study sample 29
3.4 Data collection tools 30

3.4.1 Recruitment and obtaining informed consent 30
3.4.2 Semi-structured interviews 30
3.5 Research process 31
3.5.1 Data collection 31
3.5.2 Data management 31
3.5.3 Data analysis 32
3.6 Trustworthiness of the study 32
3.6.1 Credibility 33
3.6.1.1 Clarifying researcher bias 33
3.6.1.2 Demonstrating prolonged engagement 33
3.6.1.3 Triangulation of information 34
3.6.1.4 Member checking 34
3.6.2 Transferability 34
3.6.3 Dependability 34
3.6.3.1 Independent scrutiny of data 35
3.6.3.2 Data saturation 35
3.7 Ethical considerations 35
3.7.1 Approvals and permission obtained 35
3.7.2 Ethical guidelines 35
3.7.2.1 Obtaining informed consent 35
3.7.2.2 Avoiding harm in collecting data 36
3.7.2.3 Maintaining confidentiality 36
3.7.2.4 Avoiding deception of participants 36
3.8 Conclusion 37
CHAPTER 4 38
PRESENTATION OF FINDINGS 38
4.1 Introduction 38

4.2 Demographics of participants 38
4.3 Findings relating to the first research question 38
4.3.1 Theme 1: Inability to fully benefit from hospitalisation 39
4.3.1.1 Internal pressures leading to discharge 40
4.3.1.2 External pressures leading to discharge 41
4.3.1.3 Inability to fully benefit from the therapeutic programme 45
4.3.1.4 Conclusion of theme one 51
4.3.2 Theme 2: Life was not what I expected it to be after discharge 52
4.3.2.1 Life is still the same 54
4.3.2.2 Life “inside the hospital” is different to life “outside” 59
4.3.2.3 You struggle to implement coping skills and deal with stressors 68
4.3.2.4 Conclusion of theme two 74
4.3.3 Theme 3: I did not feel supported after discharge 75
4.3.3.1 My illness was used against me 76
4.3.3.2 There are obstacles in seeking and providing support 79
4.3.3.3 Conclusion to theme three 84
4.4 Findings relating to the second research question 85
4.4.1 Theme 4: Support groups could be valuable 85
4.4.1.1 A support group would help me cope with life 86
4.4.1.2 Support groups could do more harm than good 91
4.4.1.3 I prefer a familiar environment 92
4.4.1.4 Conclusion to Theme four 93
4.5 Main findings of the study 94
CHAPTER 5 95
DISCUSSION 95
5.1 Introduction 95
5.2 Challenges faced by MHCUs that contributed to readmission 95

5.2.1 Inability to fully benefit from hospitalisation 95
5.2.1.1 Cognitive symptoms of depression 96
5.2.1.2 The emotional experience of psychiatric hospitalisation 97
5.2.1.3 The length of stay in hospital 99
5.2.2 Life was not what I expected it to be after discharge 100
5.2.2.1 Unrealistic expectations regarding the recovery process 101
5.2.2.2 Restricted sense of responsibility 102
5.2.3 I did not feel supported after discharge 103
5.2.3.1 The absence of transitional discharge 104
5.2.3.2 The support structure's unfulfilled need for support 106
5.2.3.3 Withdrawal from activities and relationships 108
5.3 Support groups could be valuable 110
5.3.1 Support groups as creating a conducive learning environment 111
5.3.2 Support groups as means of supporting ongoing recovery 112
5.3.3 Support groups as a place to experience connectedness 113
5.3.4 Support groups as a place of emotional vulnerability 114
5.4 Implications for service delivery in occupational therapy 115
5.5. Conclusion 116
CHAPTER 6 118
CONCLUSION 118
6.1 Introduction 118
6.2 Main findings 118
6.3 Limitations of the study 120
6.4 Recommendations 121
6.4.1 Recommendations for occupational therapists 121
6.4.2 Recommendations for future research 122
6.5 Concluding the research 122

REFERENCES 123
Appendix A: Interview Schedule 135
Appendix B: Ethical clearance 136
Appendix C: Denmar Specialist Psychiatric Hospital consent form 137
Appendix D: Participant consent form for participation in study 138
Appendix E: Participant consent form for electronic recording of interviews 139
Appendix F: Participant information sheet 140
Appendix G: Bracketing 141

LIST OF TABLES

Table 4.1 Sub-themes, clusters and meaning units of theme one 39

Table 4.2 Sub-themes, clusters and meaning units of theme two 53

Table 4.3 Sub-themes, clusters and meaning units of theme three 75

Table 4.4 Sub-themes, clusters and meaning units of theme four 86

LIST OF FIGURES

Figure 4.1 Factors contributing to the inability to fully benefit fromhospitalisation. ... 52

Figure 4.2 Factors contributing to the realisation that life was not what it was expected to be..... 74

Figure 4.3 Factors contributing to the experience of not feeling supported after discharge..... 85

Figure 4.4 Diagram illustrating perceptions regarding support group attendance after discharge..... 94

DEFINITION OF TERMS

Perception

The process or state of being aware of something, insight or knowledge gained by thinking, an opinion or belief (1). Participants' experiences of challenges drove their perception of factors that contributed to their readmission.

Occupational performance

Occupational performance can be described as engagement in meaningful and purposeful activities that relate to habits, routines and roles (2).

Thematic groups

Designed to help members learn the knowledge, skills and attitudes necessary for accomplishing a specific set of activities. Educational groups that use a teaching approach are included in this category (3).

Remission

The absence of both sad mood and reduced interest and no more than three of the remaining seven symptoms of a major depressive episode are present. This state has to be maintained for at least three consecutive weeks (4)(5).

Partial remission

Remission but with the presence of poorly defined residual symptoms (6).

Relapse

When the symptoms of depression re-appear, following the onset of remission, but before the criteria for recovery is fulfilled (4)(5).

Recurrence

The development of a new episode of depression, after a MHCU has recovered.

Recovery

Recovery is an extended period of remission, at least four months of remission, during which continued wellbeing is anticipated (4)(5).

Note: It became clear during a review of current literature, that the terms “recurrence” and “relapse” are used inter-changeably. For the remainder of this document, the allowance for using both terms will be maintained.

ABBREVIATIONS

MHCU – Mental Health Care User

MDD – Major Depressive Disorder

CHAPTER 1
INTRODUCTION

1.1 Introduction

This chapter provides an overview of the phenomenon that was explored. In addition to providing background information, this chapter also introduces the problem statement, research questions, aims and objectives of the study. Lastly, it reflects on the justification for this study.

1.2 Background to the study

The researcher, while employed as an occupational therapist at a Private Psychiatric Hospital, developed a keen interest in Major Depressive Disorder (MDD) as a condition. While working with Mental Health Care Users (MHCUs) diagnosed with this condition it was observed that although they made great gains during in-patient treatment, they faced considerable difficulties after discharge, which negatively affected their ability to resume their previous activities of daily living. The researcher had limited insight into the nature and extent of these difficulties, which led to this study.

Major Depressive Disorder (MDD) is a serious and recurrent disorder which is predicted to be the leading cause of disability worldwide by 2030 (6). It is estimated to affect 350 million people worldwide (7). Although MDD is a worldwide phenomenon, epidemiological differences have been noted. Lifetime prevalence estimates range from 1,0% in Eastern Europe to 16,9% in Northern America, while 12-month prevalence estimates range between 0,3% to 10% in these countries. A further difference exists in the averages between low-middle income countries with a prevalence of 11,1% and high income countries with a prevalence of 14,6% (8). South Africa is reported to have a lifetime prevalence of 9,8% and a 12-month prevalence of 4,9% (9). This is in accordance with a 9,75% lifetime prevalence rate as determined by the South African Stress and Health (SASH) study (10,11) which means that one in 10 South Africans will be faced with MDD in their lifetime (12). However, the prevalence of depression in rural communities is much higher, with a prevalence rate of 31,4% (13).

Major Depressive Disorder has a debilitating effect on all areas of a person's occupational performance. More than 90% of people diagnosed with depression in South Africa reported "global role impairment" on the Sheehan Disability Scale, which indicates that they were unable to perform their normal role responsibilities and related activities (10). This includes the ability to work and earn an income, as MDD has been associated with 27,2% of annual sick days taken in South Africa (14). Major Depressive Disorder has been associated with the development of coronary heart disease (15) (16) as well as diabetes (17).

In addition to the ability to work, a person's level of self-care, ability to sleep, participation in meaningful leisure activities as well as the ability to engage in interpersonal relationships may be affected (18). Emotional functioning, coping with domestic life and work as well as the ability to interact with others are experienced as particularly challenging (19). Major Depressive Disorder also has a major impact on the ability to parent (20)(21). Furthermore, the quality of life of individuals diagnosed with MDD is also greatly compromised (22)(23). This impairment is proportional to the severity of depressive symptoms (24). The severity of the symptoms and associated risk factors including suicide (25,26) frequently result in MHCUs diagnosed with MDD being admitted to both public and private psychiatric hospitals.

The treatment of MDD historically includes the use of anti-depressants and psychotherapy (27). More recently, the effectiveness of physical exercise (28), occupational therapy (29)(30)and mindfulness-based cognitive therapy (31) in combination with other treatments have come to light.

Despite great treatment advances that results in the improvement of symptoms, impaired functioning (32) and reduced quality of life (33) can persist even after recovery from depressive symptoms. In turn, lower levels of psycho-social functioning, amongst other factors, puts a person at risk of recurrence of the disorder (34). Relapse and re-admission rates for MHCUs diagnosed with MDD described in the literature vary. Seemüller et al. (35) reported a readmission rate of 11.9% after six months and a one-year readmission rate of 25.5%. A review by Hardeveld, Spijker, De Graaf, Nolen & Beekman (36) reported the risk of recurrence in mental health care users (MHCUs) admitted to specialised mental health care units one

year after the onset of recovery as between 21% and 37% indicating the chronic nature of the disorder. Although not each recurrence of the disorder leads to readmission, a substantial number of MHCUs are affected to such an extent, that readmission to a mental health unit is indicated.

This study took place at a Private Psychiatric Hospital in South Africa. Although MHCU's were admitted with a range of mental health problems, the majority of the MHCU's were diagnosed with Mood Disorders, including MDD. These MHCU's were typically high-functioning individuals prior to the onset of the illness and came from middle-class, privileged socio-economic backgrounds. The average length of admission was two weeks.

Occupational therapy played an integral part in the treatment of MHCU's diagnosed with MDD. The focus of intervention was on facilitating insight into MHCUs' symptoms and behaviour, as well as the impact that MDD had on their occupational performance and occupational roles (37). Occupational therapy intervention also aimed at improving insight regarding stressors which often precipitate episodes of MDD as well as developing coping skills, enabling MHCU's to function more effectively after discharge (38). Referred MHCUs attended a daily therapeutic inpatient programme presented by the occupational therapists during the period of their admission.

Shortly before discharge, all MHCUs attended a "preparation for discharge" group. The aim of this group was to reflect on the experience of hospitalisation, to identify which coping skills were specifically applicable to the MHCUs' life situations, to discuss expectations as well as set goals for the period following discharge. The MHCUs' responses in this group were varied. In spite of acquiring new skills while in hospital, those MHCUs diagnosed with MDD frequently presented with a low personal causation and felt uncertain about their ability to implement the newly acquired skills into their home and work environments. They experienced the hospital as a safe and nurturing environment, and often described the transition between hospital and home as "daunting". While other MHCUs on the other hand, felt well equipped and competent to return home.

Although MHCUs maintained contact with their treating psychiatrist and psychologist after discharge, there were no follow-up opportunities for MHCUs to access

occupational therapy services. A study by Nikendei et al. (39) reported that MHCUs diagnosed with MDD found it difficult to transfer coping skills that they have acquired during hospitalisation to their everyday life situations, it would have been of importance for the occupational therapists to know whether the coping skills taught in the occupational therapy programme were being successfully implemented at home. Also, as the transition between hospital and home has been reported to be challenging by Reynolds et al. (40), this is the time that MHCUs might have needed support and guidance with the implementation of coping skills. However, a lack of post-discharge follow-up resulted in the occupational therapists being unaware of any occupational performance difficulties that MHCUs faced when trying to re-establish their life at home, at work and in their social environment. This limited the degree to which the therapeutic in-patient programme could be adapted, in order to provide therapy that was meaningful and relevant.

1.3 Problem statement

A record review of MHCUs diagnosed with MDD at the Private Psychiatric Hospital used as the research setting for this study, revealed a six-month readmission rate of 7.6% and 7.5% respectively for 2005 and 2006, and a 12-month readmission rate of 32.9% and 35.3% respectively for the same years. Although the six-month readmission rates at the hospital are relatively low compared to those in the literature, it still means that 85 MHCUs in 2005 and 86 MHCUs in 2006 were re-admitted reporting that they were unable to cope, despite intensive group-work treatment during hospitalisation. Re-admission to hospital is expensive and the need for readmission might indicate that MHCUs have not been able to maintain gains achieved while in the hospital, nor transitioned successfully back into their contexts and re-established their occupational roles and responsibilities.

Challenges faced by MHCUs post-discharge were not known to the involved occupational therapist, which limited the appropriate modification of the therapeutic in-patient programme to ensure that these MHCUs' specific therapeutic needs were met. It was also not evident whether a follow-up, outpatient occupational therapy service in the form of support groups might help to bridge the gap between hospitalization and the demands of coping in the community, by providing support and guidance with the implementation of coping skills.

1.4 Research questions

- Which factors did MHCUs diagnosed with MDD perceive to have hampered their recovery and contributed to their readmission within a six-month period after discharge?
- What were re-admitted MHCUs' perceptions of the value of a potential outpatient occupational therapy support group post-discharge?

1.5 Aim of the study

The aim of this study was to explore the challenges that MHCUs diagnosed with MDD faced which they perceive to have impaired their occupational performance and hampered their recovery from the disorder. Furthermore, the research also aimed to explore if an outpatient occupational therapy support group would assist in maintaining the therapeutic gains made while an in-patient and assist MHCUs to deal with the challenges that they face upon discharge.

1.6 Objectives of the study

- To describe the post-discharge challenges faced by MHCU's diagnosed with MDD that contributed to their relapse and re-admission to a Private Psychiatric Hospital.
- To determine the possible value of an outpatient occupational therapy support group post-discharge.

1.7 Justification of the study

Client-centred practice is a cornerstone of occupational therapy practice, in which a client's personal experiences and knowledge should be recognised (41).
This study is essential to the provision of an evidenced-based clinical service. The anticipated outcome of the study will enable occupational therapists to identify and anticipate perceived difficulties that MHCU's diagnosed with MDD might encounter that could lead to early readmission. It would also provide insight into the possible value of an occupational therapy support group for MHCU's with MDD after discharge to assist with re-establishing of occupational roles and responsibilities.

Based on results of the study, recommendations will be made to the hospital authorities and the occupational therapy team, regarding the current in-patient

programme at the Private Psychiatric Hospital as well as possibly instituting post-discharge occupational therapy support groups if results indicated that such a support group would meet the needs of this particular cohort of MHCUs.
This feedback can be seen as a form of service user involvement in the evaluation of Occupational Therapy services at the hospital, in line with a pluralistic model of service evaluation where the perspectives of MHCU's are given equal authority to that of clinicians and other stakeholders (42).

1.8 Outline of the study

This study undertaken will be reported in the following five chapters:

Chapter 2 presents the literature review, which addressed the challenges associated with living with MDD as well as the role of support groups in the management of the disorder. Chapter 3 outlines the methodology that guided this study and described the study population, sampling method, methods used to collect and analyse quantitative as well as qualitative data. Chapter 4 presents the findings of the study on the challenges that participants experienced after discharge that contributed to their readmission, as well the potential value of support groups after discharge. Chapter 5 presents the discussion of the results outlined in Chapter 4 in the light of current literature. Chapter 6 presents the main findings of this study, as well as the conclusion and recommendations.

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

This review of the literature considered the symptoms and course of MDD, with a focus on the factors that contribute to recurrence of the disorder. As this study used a qualitative style of inquiry, the lived experience of MDD as well as recurrent MDD were also explored. Theories aimed at explaining recurrence were discussed and the implications of recurrence and readmission to hospital were addressed. Recovery from MDD was discussed in the light of the Recovery Model, including factors which have been found to contribute to recovery. The role of support in the recovery of MDD was also examined, including the value of peer support groups and online support groups.

The literature search was conducted using the following databases: ProQuest, Cochrane, PsycINFO, Cinahl and Pubmed.

2.2 Symptoms of Major Depressive Disorder

Amongst the symptoms of MDD, a depressed mood and loss of interest in pleasurable activities are the most indicative of the disorder. Other symptoms include loss of energy, change in sleep pattern, decreased appetite, psychomotor retardation, feelings of worthlessness, recurrent suicidal thoughts and diminished concentration (43).

The cognitive symptoms of depression are specifically of importance, as cognitive impairment persists after the other symptoms of depression had remitted (44)(45). A study by Gillis, Wilhelm, Batchelor & Burke (46) showed that cognitive abnormalities were present up to a decade after clinical recovery. Cognitive impairment also worsens with repeated depressive episodes (47).

Major Depressive Disorder affects different domains of cognition. A meta-analysis by Lee, Hermens, Porter and Redoblado-Hodge (48) reported that MDD negatively impacted memory, psychomotor speed and attention. As attention and memory are

prerequisite cognitive factors for learning to take place, cognitive impairment in MDD is therefore linked to impaired learning (49)(50).

While it is known that executive deficits are common in various psychiatric disorders, there is a strong argument that executive functions are particularly compromised in MDD (51)(48). Executive functions are involved in complex cognitions such as solving new problems, adapting behaviour when new information becomes available and generating different strategies which can be used in problem-solving (52).

2.3 The course of Major Depressive Disorder

Major Depressive Disorder tends to have a chronic course (53). Thus, for some MHCU's, the disorder will not involve a single depressive episode, but will be characterised by a lifetime of recurrence, relapse and possible re-admission. On average, a person diagnosed with MDD will have five to nine depressive episodes in their lifetime (54). However, MHCUs tend to delay seeking help for MDD (55,56).

Relapse rates of MHCU's with an index episode of MDD as described in global literature, vary. What is clear though is that the risk of relapse increases with each subsequent episode of depression. Gili, Vicens, Roca, Andersen & McMillan (57) as well as Gelenberg (58) postulate that around 50% of MHCU's relapse after their first episode of depression. The probability of relapse increases to 70% after a second episode and 90% after a third episode. Consequently, every relapse increases the risk of future relapses (59).

Rush et al. (5) identified the first four months following and episode of MDD as the most critical, as the majority of relapses occur in that period. In a study by O'Leary, Costello, Gormley & Webb (60), 53% of MHCUs who were admitted for an index episode of MDD relapsed within the first two months after discharge. They recommended that MHCUs should be closely followed-up during that period. MHCUs need to re-adapt to their life situations without the structure, protection and support provided in hospital. The impact of the transition between hospital and home make this period one of vulnerability.

2.4 Theories and models for recurrence of Major Depressive Disorder

Several theories and models have been proposed to explain the recurrence of MDD. Scar theory proposes that something changes during an episode of depression, causing a "scar", which makes a person susceptible to repetitive episodes of the disorder. Scarring may be evident in psychosocial scarring [e.g. changes in social skills], cognitive scarring [e.g. pessimism, irrational beliefs], personality scarring [e.g. being in a negative emotional state] and stressful life event scarring [e.g. whether someone becomes more sensitive to the effects of stressful events] (54). In support of the effect of emotional scarring, a study by van Rijsbergen et al. (61) found that a higher number of previous depressive episodes was associated with a higher level of sad mood, even when a MHCU was in remission. However, a review study by Burcusa (54) only found indications in support of personality scarring and scarring caused by stressful life events.

Contrary to the above, Backs-Dermott, Dobson & Jones (62) found no indications for relapse risk due to scarring caused by stressful life events. In their study aimed at presenting an integrated model for depression relapse, the results indicated that relapse risk was significantly linked to the experience of interpersonal difficulties, as well as emotion-based coping and avoidance-based coping. However, the stress generated by interpersonal difficulties had to be ongoing to be of significance. Therefore, it was proposed that ongoing stress depletes a person's resources putting them at risk of relapse. Even severe life stress, if resolved within a relatively short period of time, does not increase the risk of relapse. Chronicity of stress has been reported to be the decisive factor.

In a widely cited article by Post (63), the biological mechanisms underlying recurrence of depression were explored. The kindling hypothesis was proposed, which stated that both the stressors precipitating a depressive episode and the depressive episode itself might result in biological changes that make a person more susceptible for subsequent depressive episodes. The kindling hypothesis was confirmed in a study by Mitchell, Parker, Gladstone, Wilhelm & Austin (64) that stated that a severe stressful life event was more likely to precede the first episode of depression. Subsequent events that are experienced as milder in severity, can

trigger subsequent episodes of depression which suggests that MHCUs become increasingly sensitive to stressors (65). Similar to the kindling hypothesis, the stress-sensitization model suggests that less stress is required to trigger each subsequent depressive episode. Therefore, a person becomes more sensitive to the effect of stressful life events after the experience of a first episode of MDD (54).

Lastly, the Stress-generation model echoes the Kindling hypothesis and stress-sensitization model in that it suggests that depression can increase someone's susceptibility for stressful events. However, the Stress-generation model proposes that this susceptibility is partly influenced by the MHCU them self. Hammen (66) proposed that MHCU's might generate more stressful situations compared to those of a control group, based on their symptoms and behaviours (66). The Stress-generation model was supported by McNaughton, Patterson, Irwin & Grant (67) who stated that stressful life events might be the product of dysfunctional behaviour, thus in effect "created" by someone diagnosed with MDD.

In conclusion, recurrence models indicate that interpersonal difficulties, a high number of previous MDD episodes as well as stressful life events, specifically the presence of chronic stressors, increase a person's vulnerability for MDD to reoccur.

2.5 The implications of relapse and readmission

Mental Health Care Users seem to become more vulnerable with each new episode of depression. Repeated episodes of depression frequently require readmissions, which while beneficial to the treatment of the condition, are disruptive in nature. Each admission to hospital has financial, social and emotional implications for the MHCU.

Firstly, there is evidence to suggest that the intensity of depressive symptoms and the accompanying emotional distress increase with each subsequent episode. A study by Rybakowski, Nawacka & Kiejna (68) which compared MHCUs with a first episode of MDD to those with a second or third episode, found that the intensity of depressive symptoms (as measured on the Hamilton Depression Rating scale), was lowest in those experiencing a first episode, and the highest in those MHCUs experiencing a third or further episode. This increase in severity of depressive episodes is echoed in a study by Kessing (69) which found that the prevalence of

severe depressive symptoms doubled between the index episode and 15th episode of depression.

Secondly, frequent psychiatric hospital admissions may lead MHCUs to believe that they might never achieve and sustain a level of “normal functioning” (70). It has to be considered whether recurrent re-admissions still have value for the MHCU and whether the holistic impact of relapse does not outweigh the initial advantages.

It could also be asked whether re-admission should be seen as an indicator of quality of care. If readmission is seen as a valid indicator or inpatient quality of care, it implies that the previous admission should be interpreted as a treatment failure. Some studies indeed suggested an association between preparedness at the point of discharge and readmission (71) as well as quality of life after hospitalisation (72).

However, other studies argue that readmission is a reflection of the quality of community services and community support, rather than an indication of the quality of care received in hospital (73). It could also be argued that readmission is a reflection of the course of psychiatric disorders themselves, with variations in the severity and duration of episodes, as well the time period between episodes (74).

2.6 Risk factors for the recurrence of Major Depressive Disorder

It is important to identify risk factors that are associated with recurrence of MDD, as knowledge regarding these risks could contribute to the prevention of recurrence. There is considerable literature on factors that predict the recurrence of MDD, mostly quantitative in nature. As a recurrence of depression with severe symptoms could lead to re-admission, these factors were also included in this review of the literature. Following the discussion of the clinical risk factors, the MHCU perspective on difficulties related to MDD and the recurrence thereof will be discussed.

2.6.1 Clinical risk factors associated with the recurrence of Major Depressive Disorder

There is little agreement amongst researchers regarding whether or not there is an association between a specific risk factor and recurrence of the illness. These discrepancies can partly be ascribed to methodological differences: sample selection and size, which assessments were used, how recurrence was defined as well as the number of prior episodes (34). Although there is considerable literature available on

the risk factors associated with the recurrence of MDD, not all of these categories are directly relevant to this study. The following categories of risks have been selected as appropriate to this study and will be briefly discussed: Risk factors associated with the course and impact of MDD, personal attributes associated with increased risk as well as psychosocial risk factors.

2.6.1.1 Course and impact of MDD episodes

An early age of onset of the first episode of MDD has been strongly associated with increased severity of symptoms as well as an increased risk of recurrence (75). Furthermore, the severity of the first episode [whether it is expressed as the presence of specific symptoms like suicidality, a greater number of symptoms or higher scores on standardised Depression Scales e.g. Hamilton] has also been directly linked to the risk of recurrence (54)(76). However, the duration of the first episode of depression does not appear to be related to an increased risk (54).

The Individual Burden of Illness **I**ndex for Depression (IBI-D) reflects the degree to which a MHCU is suffering from depression. The measure incorporates symptom severity, impairment in functioning and reduction in quality of life as reported by MHCUs. In a study by IsHak, Greenberg & Cohen (77) it was concluded that relapse was more likely in MHCUs with a higher IBI-D and is thus considered to be a risk factor.

The presence of comorbid psychopathology has also been associated with increased risk of recurrence (53). In the presence of high levels of anxiety, greater severity of depressive symptoms, increased functional impairment and a more chronic course of depression have been reported compared to MHCUs without clinically meaningful levels of anxiety (78)(79).

Previous psychiatric history was the most important predictor of readmissions in a recent study by Donisi, Tedeschi, Salazzari & Amaddeo (80). However, only 30% of their study population consisted of MHCUs diagnosed with affective disorders. Mental Health Care Users diagnosed with MDD, who respond to treatment but do not achieve full remission of symptoms, have only achieved partial remission and are at a greater risk for relapse, with relapse rates of 3-6 times higher compared to MHCUs who achieved full remission (81). In a study by Paykel (82), 76% of MHCUs

with residual symptoms relapsed within 10 months from remission, compared to 25% of MHCU's who achieved full remission. Similarly, a study by Pintor, Gastó, Navarro, Torres & Fañanas (83) found a relapse rate of 67.61% for MHCUs with partial remission, as compared with a relapse rate of 15.18% for MHCUs with complete remission.

The presence of residual symptoms was also associated with a shortened period of relative wellbeing before relapse (84) and is indicative of significant impairment in psycho-social functioning (85). McIntyre & O'Donovan go so far as to state that partial remission should be considered a treatment failure (86). While it is clear that the presence of depressive symptoms at discharge increases the risk of relapse, many MHCU's are only treated until the point of response and not remission, and thus the risk of re-admission is increased.

Effective treatment of MDD requires specialised care and the treatment setting can have an influence on the risk of recurrence. Psychiatric hospitals are better equipped to treat the disorder in terms of adequately trained staff and the creation of a therapeutic environment, if compared to the care provided by general medical hospitals. It comes as no surprise then that admission to a psychiatric clinic during first admission is associated with a decreased risk for re-admission when compared to MHCUs admitted to a general hospital, which was associated with an almost three times higher risk for re-admission (87).

2.6.1.2 Personal attributes

Self-efficacy involves the ability to set goals and determines the amount of effort that someone is willing to undertake to reach goals (88). In depression care, self-efficacy is described as a MHCU's confidence in his or her ability to manage depressive symptoms and by doing so preventing a recurrence. Limited self-efficacy has been associated with the risk of relapse (89). Relying on avoidance-coping, instead of actively solving problems, has also been linked to lingering symptoms of depression (90) which in turn increases the risk of recurrence in the form of partial remission.

Non-compliance with medication has also been associated with relapse. A study by Haywood et al. (91) attributed 50% of psychiatric re-hospitalisations to medication non-compliance. When looking specifically at MDD, a recent systematic review

reported a direct link between medication non-adherence and an increased risk for recurrence of MDD and subsequent hospitalisation (92).

2.6.1.3 Psycho-social factors

Impaired psychosocial functioning has been associated with an increased recurrence risk. The Longitudinal Interval Follow-up Assessment (LIFE) was used to follow 290 subjects over the course of 15 years to determine whether psychosocial impairment is a risk factor for the recurrence of MDD. Several domains of functioning were rated, including work, interpersonal relationships, satisfaction (overall level of contentment) and recreation. Participants who have recovered from MDD, with moderately impaired psycho-social functioning at the time of a particular assessment, were more than 3 times as likely to have relapsed at the next assessment (6 or 12 months later) compared to those with very good psychosocial functioning (34).

Stressful life events seem to play a major role in the relapse of MHCU's with MDD. Studies have indicated that there is a link between relapse and the number as well as severity of life events leading up to relapse and re-admission (93)(94). Severe life events are more likely to trigger the first episode of MDD (95), while the presence of non-severe life events predict recurrence (96). Bockting, Spinhoven, Koeter, Wouters & Schene (97) confirmed this by postulating that more daily hassles is a risk factor for the recurrence of depression. Therefore, after the index episode, life events do not have to be severe to contribute to relapse.

Stressful life events not only fulfil a cumulative role that could result in re-admission, but can also be used to estimate the time between discharge and possible relapse. A study by Mundt, Reck, Backenstrass, Kronmüller & Fiedler (98) indicated that there is a relation between the number of stressful life events prior to the first admission, and the time of relapse after the MHCU has been discharged from hospital. The more stressful life events, the shorter the period between discharge and relapse.

A study by Skärsäter, Langius, Ågren, Häggström & Dencker (99) found that the subjective lack of social support and the presence of dependent stressful life events characterized MHCUs suffering from MDD. Furthermore, recovery among MHCUs who lived in unhealthy social situations was found to be limited compared to MHCUs who lived in a positive and enabling social context, regardless of the treatment that

they have received (100). The lack of social support when recovering from major depression, can lead to the recurrence of the disorder (101). It is therefore not surprising that MHCUs' ability to remain independent after discharge relies heavily on the availability of emotional support, as noted in a study by Thompson, Neighbors, Munday & Trierweiler (102). However, the end-result of their study failed to establish whether emotional support was a predictor of reduced readmission.

The experience of stigma has been reported to increase a person's vulnerability for depression. As stigma has historically been associated with "severe" psychiatric disorders e.g. schizophrenia, little research has been done on stigma associated with MDD. However, recent studies indicate that feelings of shame and a lack of confidence due to the fear of being labelled prevent or delay MHCUs diagnosed with MDD from seeking help and support (103)(104). In a large study of 1080 people diagnosed with MDD across 35 countries (105), 79% of participants experienced some form of discrimination. The experience of discrimination was an obstacle in initiating new personal relationships, applying for work or continuing education. In addition to actual experienced discrimination, anticipated discrimination prevented some MHCU from seeking appropriate help, as they did not want to be "labelled" once again. The experience of discrimination associated with stigma can therefore be seen as a barrier in the recovery process from MDD (106).

Although public stigma is the most observed form of stigma, self-stigma, when MHCUs internalise discriminatory public attitudes and endorse negative stereotypes about themselves, has also been associated with depression (107). The experience of self-stigma has a negative effect on self-esteem of someone suffering from mental illness, which in effect could increase vulnerability of depression (108).

2.6.2 Perspectives of Mental Health Care Users

There is limited literature available on the lived experience of the challenges associated with MDD, which could lead to recurrence of the disorder. This lack of literature is also mentioned by Owen-Smith et al. (109) and Cutcliffe et al. (110), whose studies will be discussed later in this chapter. Therefore, the different aspects of risk factors as it is described in the literature will be discussed.

Firstly, the literature that is available regarding the direct causes that MHCUs attribute to their depression, not necessarily recurrence, will be discussed. Secondly, as the literature does shed some light on the lived experience of recurrent MDD in general, the challenges associated with living with the chronicity of the disorder will be highlighted. Thirdly, literature on the challenges specific to the post-discharge period will be discussed.

2.6.2.1 Causal factors that MHCUs attribute their MDD to

Although the literature does provide insight into the factors that MHCUs attribute to the cause of their depression, there is not always a clear distinction in the methodology to indicate whether it involves a first episode of depression or recurrent MDD. A review study conducted in 2008 (111) which investigated the illness representations that MHCUs held for depression and anxiety, highlighted various factors which MHCUs attributed to the cause of their depression. The review found strong evidence for environmental and psychological causes, although biological causes were also identified.

The most commonly mentioned cause of depression by MHCUs with at least two prior depressive episodes, was found to be stressful life events in a study by Klein, Van Rijsbergen, Ten Doesschate, Hollon, Burger and Bockting (112). While their study made use of a basic four-item questionnaire, a study by Hansson, Chotai and Bodlund (113) asked participants one open-ended question about what they believe was the cause for their depression. Findings revealed three themes that MHCUs perceived to have caused their depression namely current life stress (including work problems, family problems, physical illness and unemployment), past life events (including death of a loved one, broken relationships and childhood trauma) as well as constitutional factors such as specific personality traits. Similarly, a recent German study (114) involving 678 participants identified similar themes to the above study, namely problems at work, problems in the social environment, internal states, negative life events, childhood difficulties and physical illness. It should be noted that although most of the participants held a primary diagnosis of MDD, participants with post traumatic stress disorder, adjustment disorder and anxiety disorders were also included in the sample. In contrast to the above-mentioned studies which mostly made use of questionnaires, a phenomenological study by Mgutshini (115) made

use of case notes, semi structured interviews as well as focus groups, allowing for a broader scope of causal factors to potentially emerge. Although his study highighted the discrepancies between the views of MHCUs and mental health practitioners which the other studies did not address, findings once again pointed to the role of situational circumstances as a causal factor for MDD. Financial problems, limited social support and the breakdown of relationships were identified as precipitants of relapse by MHCUs.

In addition to the above studies which directly explored the causal factors associated with depression, some studies in the literature focus on other aspects relating to causal factors but indirectly provide an insight into the factors that MHCUs associate with the cause of their depression. In a randomized, double-blind clinical trial (116) in which neuro-imaging was used to identify predictors of remission when different treatment modalities were used, identifying causes of participants' MDD was a component of the study. Eighty participants were presented with a seven-item questionnaire rated on a six-point scale, from strongly disagree to strongly agree. The statements referred to a chemical imbalance in the brain, pessimistic attitudes, stressful events, problems that came out of the blue and an illness that affects one emotionally instead of physically. The most commonly held causal beliefs were found to be stressful life events, a chemical imbalance and pessimistic personality traits.

Yet another line of enquiry which is explored in the literature and which indirectly provides insight into causal factors that MHCUs associated with MDD, revolves around the use of anti-depressants. When specifically asked about the nature of stressful life events leading up to the point of anti-depressants being prescribed, participants in a recent study by Hartdegen, Gibson, Cartwright and Read (117) most frequently reported relationship problems, life transitions, losses and work related difficulties. This echoes the results of another large New Zeeland study (118) involving 1829 participants who were taking antidepressants, in which relationship problems and work-related difficulties were identified as causal factors of their depression. However, in contrast to the above-mentioned study by Hartdegen et al. (117) which mostly found psycho-social difficulties to be causal factors for MDD, results of the New Zeeland study (118) also acknowledged the role of chemical and heriditary factors in the onset of depression.

2.6.2.2 The lived experience of recurrent MDD

Nystrom & Nystrom (119) thoroughly described the MHCU experience of recurrent depression. Although the difficulties that could possibly lead to another recurrence were not highlighted, it was clear how burdensome repeated episodes of depression were experienced by MHCUs. Participants described difficulty in making themselves understood when trying to communicate with others. Participants felt as though they were in a state of paralysis, the emotional pain that they experienced was so intense that it could have led to death and they found it impossible to be with themselves or with others and they felt the need to vanish so as to remove the burden from others. The experience of alienation from meaningful social relationships and pain to such an extent that it became a physical sensation, was echoed in an older study by Poslusny (120). Difficulty in participating in conversations and not undertaking any pleasant activities contributed to the realisation that one's world was getting smaller. Furthermore, extreme fatigue made it feel impossible to engage in role-responsibilities or participate in pleasant activities (121). In terms of an emotional association with relapse, worry and fear were the most prevalent emotions that MHCUs associated with relapse. In a study by Nunstedt, Nilsson, Skärsäter & Kylén (122) which used a qualitative interpretative design to explore how MHCUs understand their depression, participants described a depressive episode as a "frightening time" as they found it difficult to understand what was happening to them. Manning & Marr (123) highlighted the impact of these feelings as participants in their study described how they avoided making long-term plans due to their worry of experiencing a subsequent depressive episode. Although these accounts do not explicitly state that these difficulties result in re-admission, it can be argued that burden of living with MDD is so great that some of these difficulties might contribute to relapse.

Another relevant factor identified in a Dutch study (112) is that MHCUs tend to attribute their first episode of depression to external factors, which seem to change over time as subsequent episodes of depression are attributed to internal factors. This change may be indicative of a shift in MHCUs' causal beliefs as they are faced with recurrent episodes, or an indication that risk factors change over the cause of depressive episodes (124)(125). However, a limitation of the Dutch study was the fact that causal beliefs were retrospectivley assessed, which meant that their study

did not assess actual beliefs during a depressive episode, making results vulnerable to recall bias as participant beliefs might have changed based on more recent experiences.

Lastly, as relapse may result in readmission, the experience of psychiatric hospitalisation itself should also be considered. Psychiatric hospitalisation has been described as challenging. Stenhouse (126) reported that MHCUs often feel unsafe in acute psychiatric hospitals despite the absence of direct physical threats and questioned whether hospital environments are always conducive to recovery. Although a similar study by Jones et al. (127) found that the majority of participants experienced a sense of safety while in hospital, their findings still indicated that psychiatric wards can be experienced as volatile environments. It should therefore be considered that the experience of hospitalisation could be seen as a challenge in itself.

2.6.2.3 Post-discharge challenges

The literature indicates that difficulties are not only restricted to the period leading up to admission or during hospitalisation, as MHCUs also experience specific challenges in the immediate period after discharge. Desplenter, Laekeman & Simoens (128) employed a mixed methods approach to explore how MHCUs diagnosed with MDD progressed after discharge from hospital. They identified various difficulties relating to re-adapting to the home-environment, difficulty in finding the right medication, financial difficulties with no money to pay for follow-up consultations, as well as social difficulties that presented themselves as a perceived lack of understanding and feelings of loneliness.

Another study by Nolan, Bradley & Brimblecombe highlighted the challenges that MHCUs experienced between 2-4 weeks after discharge (70). Re-establishing social contacts after discharge was deemed problematic, even though the length of admission was only 6 weeks, which can be viewed as relatively short. Social difficulties were experiences as being so severe that participants anticipated that social isolation would probably contribute to their relapse. Structuring their day was found to be particularly challenging. Although the majority of participants acknowledged that participation in hobbies, voluntary work or church activities would be beneficial for their recovery, they lacked the confidence to take the first step.

There are some tentative findings on challenges experienced after discharge, which could result in relapse. Owen-Smith et al. (109) explored the experiences of participants following psychiatric discharge. Although the entire sample had experienced anxiety and depressive symptoms, the primary diagnoses were diverse. They explore the attitudes that participants held towards discharge as well as the stressors that they experienced post-discharge. The re-emergence of existing stressors were found to be confrontational, as participants felt protected from stressors whilst in hospital. Some stressors were found to have worsened due to hospital admission, like coming to terms with a new identity after psychiatric diagnosis as well as having to adapt at home without the support available in hospital. A study by Cutcliffe et al. (110) employed a phenomenological approach to explore the phenomenon of how being discharged from hospital contributes to ongoing suicide risk. Being fearful of leaving the safety of hospital, not feeling ready to take on the world, struggling with the ambivalence of not wanting to leave hospital but realising that it is inevitable as well as not wanting to be a burden to family members described the essence of their experience. However, both the above studies focused on identifying challenges that could contribute to suicide risk after discharge and neither explored challenges that could solely result in re-admission.

2.7 Recovery from Major Depressive Disorder

The literature distinguishes between recovery from MDD according to the medical model which involves a “cure” and recovery as an ongoing process, the “Recovery Model”, which is now advocated by many mental health professionals and MHCUs alike. Whereas the traditional medical model only views professionals as experts, the “Recovery Model” embraces a more collaborative approach in which MHCUs are viewed as experts in their experiences of a disease (129). This approach to treatment facilitates wellbeing, whilst acknowledging the reality of mental illness. It advocates active management of problematic situations and taking control of one’s life situation. The concept of recovery in the context of this model can be defined as **“**the process of changing one's attitudes, values, feelings, goals, and skills in order to live a satisfying life within the limitations caused by illness.” (130)(p527). Recovery also entails looking beyond clinical recovery, which is the absence of symptoms, to embracing recovery as an ongoing journey, in all areas of occupational importance

(131) Literature indicates that recovery should be seen as an ongoing process which consists of ebb and flow experiences (132).

Mental Health Care Users have identified various factors which they found to have contributed towards their recovery from MDD. Van Grieken, Kirkenier, Koeter, Nabitz and Schene (133) found that MHCUs who have recently recovered from an episode of MDD valued the following: having a pro-active attitude towards treatment, strategies for managing daily life (e.g. setting goals, using a timetable to schedule activities and eating healthily), taking initiative in explaining depression to other people, engaging in social activities and meaningful occupations, making a deliberate effort to take good care of oneself (e.g. having a positive mantra, establishing a good day/night rhythm and restricting the time spent on worrying), as well as seeking contact with fellow sufferers. Having contact with MHCUs facing the same struggles, also allows the opportunity to learn and use newly learnt skills in a supportive environment (134) which reflects one of the information needs of MHCUs diagnosed with MDD: knowing how to cope with the symptoms of the disorder (135).

Other positive factors relating to recovery were identified to be acceptance of the diagnosis of depression as a psychiatric illness (136) as well as acceptance of the cyclical longer-term nature MDD which requires long-term professional support (133). Therapy sessions with a trusted and understanding therapist in which the MHCU perceives to be taken seriously as well as not being put on a waiting list for therapy (137) were also factors that MHCUs valued as stepping stones to recovery.

Furthermore, the development of hope and autonomy was deemed to be of importance, as MHCUs in a study by Chambers, Cook, Thake, Foster, Shaw, Hutten, Parry, and Ricketts (138) reported to feel less depressed when they felt in control of their life situations. Also, dealing with unsolved issues in their lives and allowing themselves time to heal were found to be helpful strategies towards recovery (139).

Participation in meaningful activities can be seen as important in recovery from MDD (140) and is inherent to occupational therapy treatment. A study by Synovec (141) found that participation in occupational therapy enhances the recovery process in an inpatient psychiatric setting. Although there is evidence to suggest that the nature of the activity can be varied, (be it participation in physical activity, arts, education or

employment) the importance of participation in the process of recovery is undeniable (142).

2.8 The role of support in the recovery from Major Depressive Disorder

The availability of support can play a valuable role in the recovery from depression. Higher levels of support have been associated with lower levels of depressive symptoms (143) as well as better adjustment to life following discharge (109). Studies have shown that the availability of perceived support has a protective role in depression (144) but in order for it to be perceived as helpful, it should be aimed as meeting specific needs which are relevant to the person at that point in time (145). Skarsater et al. (99) viewed social support as an important cornerstone in restoring a person's sense of coherence. Sense of coherence refers to the extent in which a situation is viewed as manageable, meaningful and comprehensible (146) and therefore determines a person's ability to cope with stress and the subjectively perceived ability to meet demands. A MHCU's support network can play a valuable role in helping someone to view a situation as manageable, which increases their sense of coherence, which in turn is linked with recovery from major depression (99).

2.8.1 Informal support

Family and friends can offer valuable support. Literature shows that it is important for families to develop insight into the diagnosis of their loved one, as it can decrease the negative impact of depression (147). In a qualitative study by Griffiths, Crisp, Barney & Reid (148) exploring the perceived benefits and disadvantages of support from family and friends by participants who have experienced depression, several advantages were identified. Support was experienced as valuable. It encompassed "emotional support" in the form of acceptance, kindness and caring which was experienced as reassuring coming from a familiar person. "Informational support" in the form of advice was helpful in solving problems, gaining fresh perspective on situations and served as encouragement for participants to seek formal help if necessary. "Companionship support" fulfilled the need for connection with significant people in one's life while "instrumental support" included practical help with role responsibilities.

However, not all associations with confiding in friends and family were described as positive. A study by Garcia, Duberstein, Paterniti, Cipri, Kravitz and Epstein (149) concluded that negative messages that MHCUs hear regarding their depression can undermine recovery. Their study involved 15 focus groups across three American cities. Five themes emerged relating to the experience of support: feeling labelled (e.g. stating that MHCUs were always serious or lazy), feeling judged (e.g. hinting that their life circumstances were too positive to justify feeling depressed), feeling lectured (e.g. unhelpful suggestions for improving their symptoms) and feeling rejected (e.g. people disengaging from the conversation when MHCUs tried to share some of their difficulties relating to MDD). It appeared that while comments by the support network were often well-intentioned, it was negatively received by MHCUs whilst they struggled with the symptoms of MDD.

The experience of stigma was the disadvantage cited by the most participants in the study by Griffiths, Crisp, Barney & Reid (148). This included stigmatised responses e.g. “pull up your socks” or “build a bridge and get over it”, as well as the negative experience of being pitied by others. Significant others’ lack of knowledge and inappropriate support could even contribute to MHCUs’ experiences of loneliness (150).

Although literature relating to MDD tends to focus on the affected individual, recent literature has shown that being a caregiver of someone with MDD can be experienced as burdensome (151) and that the burden is comparable to that of other serious psychiatric disorders including schizophrenia (152).

Priestly & McPherson (153) conducted a meta-ethnography of 15 qualitative studies, in which individual components of various studies were taken to create a review of the experiences of living with a partner of relative with MDD. Priestly & McPerson managed to described the essence of relatives’ experiences well, by breaking down the process into four stages namely “making sense of depression”, “changes in family dynamics”, “overcoming challenges” and “moving forward”.

When family members first start noticing changes in the MHCU indicative of depression, there is a risk that they might not realize what it is initially and tend to blame themselves (154,155) as they try to make sense of what is happening. Various studies described the changes that occurred in family dynamics and the

literature shows that the impact that MDD has on family life can be profound. Radfar, Ahmadi and Khoshknab (156) conducted unstructured interviews with 26 family members of MHCUs and reported that their findings revolved around one central theme namely “a turbulent life”. Family members described how depression infiltrated the whole family and how the normal rhythm of family life was disturbed. They mentioned the presence of resentment because the needs of other family members have been neglected and also described concern for the MHCUs wellbeing and future. The disturbance of family life is highlighted in a study by Skundberg-Kletthagen, Wangensteen, Hall-Lord & Hedelin (157) in which relatives described how they had to live “on the other person’s terms” in order to accommodate their ill relative’s needs. However, they acknowledged that they compromised their own wellbeing by doing so. It is therefore not surprising that care-giver burden can result in an increased risk for significant others to develop psychiatric disorders themselves (158).

A study by Ahlström, Skärsäter and Danielson (159) included the perspectives of underage children of which a parent was diagnosed with MDD. Although their study yielded similar results to that by Radfar et.al. (156) and Skundberg-Kletthagen et.al. (157) in terms of the challenges that families encounter, their findings shone light on another relevant theme namely “living in seclusion”. Families reported that the ill family member lived on the outer edge of family life and that the family as a whole had less outside contacts, which created an experience of isolated living. However, findings also show that a way forward can be found, despite the difficulties that families face. Learning to cope with depression as a family created a better understanding of other people, which enriched their lives.

Involving family members in the process of learning about MDD, has various benefits. Literature indicates that family education for relatives of MHCUs can fulfil the need that they have for accurate information regarding the disorder (160). When relatives know more about depression, it makes it easier for them to understand the disorder and to provide appropriate support (157). Furthermore, learning about MDD can help relatives to accept the diagnosis, reduce stress associated with their relative’s illness and improve their own problem-solving ability (161).

2.8.2 Structured support

In addition to support from significant others, various other models of support were identified in the literature that MHCUs suffering from MDD valued. These include support groups run by therapists, by peers (162)(163), internet support groups (164)(165)(166) as well as telephone-delivered support services.

In a study by Jarchow (167) describing women's experiences living with depression, attending support groups was identified as being the most helpful in facilitating their recovery from depression. Various other benefits of peer support in the management of depression have been identified in the literature. Peer support promotes recovery by promoting self-efficacy, instilling hope, sharing knowledge and modelling coping skills (168). Support was also identified to help to decrease the effects of stigmatisation by boosting self-esteem (169), as sharing a diagnosis can normalize the experience of a psychiatric disorder (170) (134). Participants also reported that their depressive symptoms were alleviated (165).

However, not all results regarding the value of support groups are positive. In one study, 11% of participants felt lonelier after making use of an online depression forum (171). Negative social comparisons, the risk of receiving unhelpful advice and poor cohesion were cited as reasons for disliking the group. Despite these negative results, depressive as well as anxiety symptoms still improved, social isolation decreased and life satisfaction improved (172).

2.8.3 Transitional discharge

The literature indicates that transitional discharge can be viewed as a further form of support on offer to MHCUs diagnosed with MDD, as the transition between hospital and home can be a daunting experience (106). A review by Vigod (173) indicated that psychiatric readmission rates could be reduced by smoothing the transition between in-patient care and outpatient treatment. However, a recent study by Bonsack (174) concluded that transitional case management did not significantly reduce the one-year readmission rate. Although these studies present conflicting results, the possible risk associated with non-gradual discharge has resulted in the development of transitional care programs, with the aim of supporting the transition from hospital to home. Continued engagement in psychiatric care, support group

attendance (175), family involvement (176) as well as the overlap of in-patient and community staff have been found to aid with the transition from hospital to home .

2.9 Conclusion

This literature search highlighted the complex factors that play a role in the course of MDD. It also presented a current paucity of qualitative studies on the challenges experienced by MHCU diagnosed with MDD as well as the role of support in the recovery. However, the lived experiences of challenges associated with MDD, specifically in a South African context remains mainly unreported, which validates the need for further research.

CHAPTER 3
METHODOLOGY

3.1 Introduction

The aim of this chapter is to describe the research methods employed for this study. The research approach and design are reported as well as the worldview that informed the research. This chapter also provides an overview of the research procedure, including a description of the sampling method, data collection and data analysis. Finally, the trustworthiness of the study and ethical issues are addressed.

3.2 Research approach and design

3.2.1 Worldview

A worldview or paradigm refers to “a set of basic beliefs” which defines “the nature of the world, the individuals place in it and the range of possible relationships to that world and its parts” for the holder of that specific worldview (177)(p107). Although the worldview remains mostly hidden in research, it should be acknowledged as it influences the researcher’s approach to the study.

In this study, the researcher used a social constructionist worldview. This implies that people try to make sense of the world in which they live through interaction with others. When employing this worldview in research, the participants’ views of situations are held in high regard. Open-ended questioning is advised as it allows the researcher to listen carefully to the meanings that people attach to their life experiences. Although social constructivism is usually used in phenomenological research as means of interpretation of the meanings that people attach to situations, it is also well-suited for a descriptive study in which the experiences of individuals are described.

Constructivism involves philosophical assumptions, as described by Guba and Lincoln (177). Firstly, the ontological assumption answers questions about the nature of reality. Constructivism employs a relativist ontology, as reality is subjective and created in the minds of participants. In this study, the researcher used quotes in the words of participants to portray their reality (178), which was participants perception

of factors that contributed to their readmission. Secondly, the epistemological assumption answers questions about the relationship between the researcher and that which is being studied. The constructionist worldview holds transactional and subjectivist assumptions, meaning that the researcher and participants are interactively linked and that knowledge is created in their interaction (177). In line with constructivism, the researcher attempted to lessen the distance between herself and participants, by using a qualitative research approach as well as semi-structured interviews for data gathering, which allowed for participants' perceptions about factors that lead to readmission to emerge.

3.2.2 Research approach

This study followed a qualitative approach. Qualitative research was used to investigate the participants' perception of the challenges following discharge as experienced in their everyday life. This study used non-statistical methods and descriptive data to reflect the participants' own words. The study was more concerned with understanding the lived experience of the challenges that led to the readmission of participants diagnosed with MDD as well as their perception of the value of support groups after discharge, than explaining it. It therefore valued the subjective view of participants as someone who has first-hand experience of the challenges that MHCUs face after discharge (179).

3.2.3 Research design

A descriptive design offers a "comprehensive summary of an event in the everyday terms of those events" (180)(p334). This research design allows the researcher to stay close to the data and therefore close the meanings that participants attached to the information that they shared. The researcher wanted to convey the challenges that participants experienced after discharge, which they perceived to have contributed to their readmission, as well their perception of the value of support groups as closely as possible to their lived experience without attaching any form of interpretation to it. Although there are many qualitative designs that can be used (178), a descriptive design was deemed most suitable for this study.

3.2.4 Research setting

This study was conducted at a Private Psychiatric Hospital, that specialised in the treatment of Mood Disorders and Anxiety Disorders. At the time of this study, the hospital consisted of four wards which were situated in a park-like garden: two female wards, one male ward and one mixed ward. The hospital offered accommodation in single, twin and four-bedded rooms. Mental health care users were orientated to the hospital setting by nursing staff upon admission and weekly activity schedules were displayed in the wards by the occupational therapists.

The multidisciplinary team that offered professional services consisted of psychiatrists, nurses, psychologists, occupational therapists, as well as a sessional social worker and music therapist. The occupational therapy programme consisted of occupation-based groups that used participation in sport and craft as treatment modality, as well as thematic groups that played an important role in the learning of coping skills. Thematic groups included the following topics: problem solving, stress management, the development of personal insight, conflict and time management.

3.3 Sampling

3.3.1 Study population

The population of this study consisted of all the MHCUs with a diagnosis of MDD who had been re-admitted to the Private Psychiatric Hospital used as research setting within six months of discharge.

3.3.2 Study sample

A purposive sampling strategy (179) was used in this study, as the sample was composed of MHCUs who were information-rich, contained the most characteristic attributes of the population and who adhered to specific inclusion criteria. Purposive sampling implied that the sample size was not set at the onset of the study but participants were added to the sample until the data was saturated. To add another layer to sampling, purposive sampling was followed by sequential sampling in which every third MHCU that met the inclusion criteria was invited to participate in the study.

Inclusion criteria:

- First re-admission to the Private Psychiatric Hospital which was used as research setting.
- Re-admission within 6 months of discharge.
- Diagnosis of MDD as confirmed by the treating psychiatrist.
- Adult MHCUs (age: 18 – 65 years old).
- Ability to converse in Afrikaans or English as the researcher conducted the semi-structured interviews in both of these languages.

3.4 Data collection tools

3.4.1 Recruitment and obtaining informed consent

The researcher obtained daily captured data from the hospital's electronic patient system, which was used to identify MHCUs who fulfilled the inclusion criteria for the study. Structured preliminary interviews were arranged with each MHCU as soon as their re-admission was made known to the researcher. The expectation was that interviews would be conducted within three days of readmission.

The purpose of preliminary interviews was for the researcher to introduce herself to the MHCUs, recruit them for the study by explaining the study to them and to gain their consent. The purpose of the research, the reason for the MHCU's possible involvement, approximate duration of the interview, how responses would be recorded as well as the issue of confidentiality were explained.

3.4.2 Semi-structured interviews

Semi-structured interviews were used to gather data. As interviewing facilitates the unfolding of participants' stories, it was deemed appropriate as the researcher wanted to explore the MHCUs' experiences from their point of view (179). Based on the social constructionist worldview, participants were viewed as the 'experts' regarding the challenges they experienced after discharge, which they perceived to have contributed to their readmission. Mental Health Care Users were also viewed as the 'experts' regarding the possible value of support groups and were therefore given the opportunity to share their experience.

A set of predetermined questions, referred to as the interview schedule was used for the interviews (Appendix A). These questions only served as a guide to allow the participants' response to influence the course that the interview took. When necessary, gentle prompting was used to ensure a clear understanding of what the participant said.

3.5 Research process

3.5.1 Data collection

All participants were interviewed according to the same interview schedule once they had consented to participate. Interviews took place in a quiet room adjoining one of the hospital wards. Participants were made comfortable before the start of the interview. The researcher attempted to establish good rapport with the participants by active listening and showing an interest in what they said.

During the interviews, questions were mostly open-ended to encourage expression of the participant ideas and the interview lasted between 45 and 60 minutes. The major points of discussion were summarized toward the end of the interview, to "wind-down" the conversation. Participants were invited to ask questions or add to anything that has been discussed and were thanked for their participation.

Where possible, participants were approached the day following the interview to invite them to a follow-up interview, to add information. All participants declined the invitation to the second interview, stating that they did not have any further information to add.

One participant received Electro Convulsive Therapy (ECT) during her re-admission. As ECT can result in short-term cognitive deficits (181), her treatment was taken into account and she was not interviewed on the day that she received ECT.

3.5.2 Data management

Eleven audiotaped interviews were transcribed verbatim for further data analysis. The researcher chose to be personally involved in the transcribing process. This included listening to recordings several times, transcribing information manually and writing down nuances that participants brought to the interview e.g. sighing or

silences. All of the above allowed the researcher to become immersed in the research material resulting in greater familiarisation with the data.

3.5.3 Data analysis

Data analysis can be defined as “the process of bringing order, structure and meaning to the mass of collected data” (179)(p333). According to Creswell (178) the basic three steps of qualitative data analysis involves preparing the data in the form of transcripts, then reducing the data into themes and finally presenting the data in a final discussion. He acknowledged that there is room for variation in this approach. Creswell’s method of data analysis, which draws on the analysis procedures of Colaizzi’s descriptive phenomenological data analysis (182), was used in this study.

Firstly, transcripts were read and re-read several times. Secondly, significant statements were developed. Every statement made by a participant that was viewed as relevant to their experience of the phenomenon was listed. Each of these significant statements was treated as being equal in worth; this is referred to as “horizonalization” of the data. Thirdly, the researcher reflected on what the significant statements meant. Formulating these meanings added another layer of analysis. A meaning was attached to each significant statement. These meaning units served as basic codes as the researcher started identifying common concepts. Each meaning unit was linked to a letter of the alphabet, written down and pinned to a notice board to create an oversight of the meanings that have been formulated. With each new interview, novel meaning units were added to those already pinned to the board. When similar wording occured, meaning units were assimilated. Fourthly, meaning units were grouped together, resulting in 26 clusters, which allowed for the emergence of 11 sub-themes and four themes. Therefore, data was organised into increasingly abstract information units to form categories and themes, using a “bottom up” or inductive coding approach (178). Coding was checked by re-reading data and relevant quotes were added to clusters.

3.6 Trustworthiness of the study

The concept of validity in qualitative research has been through a process of adaptations. Initial applications were taken directly from the reliability (stability of findings) and validity (truthfulness of findings) standards of quantitative research.

However, these terms proved to be incompatible with the interpretive perspective of qualitative research (183). Qualitative analysis is inherently subjective because the researcher is the instrument for analysis (184).

Although Angen (185)(p387) suggested that validation in qualitative research should be viewed as “a judgement of the trustworthiness or goodness of a piece of research”, Creswell (178) gave preference to using the term “validation” in order to emphasise a process, as opposed to using historical words such as “trustworthiness” or “credibility”. He further acknowledged that validation in qualitative research now has an emphasis on researcher reflexivity.

As described by Lincoln and Guba (186) and in line with a constructivist worldview, the following strategies were employed in this study to achieve credibility, transferability and dependability (177):

3.6.1 Credibility

3.6.1.1 Clarifying researcher bias

Bracketing is the process by which a researcher temporarily sets aside her own assumptions and prior knowledge regarding the phenomenon, in an attempt to understand the phenomenon from the participants’ point of view (187). It enables a researcher to look at participant accounts with an open mind (184). In this study, bracketing was done by means of a written reflection which is included in Appendix B. Furthermore, the literature review of this study was done after data collection and analysis to further prevent researcher bias. Reviewing the literature before data collection and analysis poses the risk that prior knowledge of current literature might influence the data collection process and skew data analysis.

3.6.1.2 Demonstrating prolonged engagement

The researcher was employed as occupational therapist at the Private Psychiatric Hospital at the time of the study and presented thematic groups, sport sessions and craft groups. As the researcher was present every day at the site where the research was conducted, it enabled participants to become acquainted with the researcher in different settings and to build a degree of trust.

Furthermore, prolonged engagement with the data was established by recording interviews, listening to the interviews repeatedly, personally transcribing each interview as well as reading and re-reading transcripts in the process of data analysis.

3.6.1.3 Triangulation of information

In triangulation, different sources are used to confirm evidence. In this study, data that were gathered through semi-structured interviews as well as a literature review, were analysed and compared with each other.

3.6.1.4 Member checking

Member checking involves taking findings back to participants so that they can judge the credibility thereof. As participants were only admitted for an average of two weeks and were discharged before data analysis was complete, it was not possible to employ member checking as strategy.

3.6.2 Transferability

Thick, rich descriptions were used to describe the setting in which this study took place (chapter one) as well as participants' experiences of challenges post-discharge (chapter four). This allows readers of this study to determine how applicable findings would be to their setting and whether findings can be transferred to other contexts (178), as it is not the intention of qualitative research to be fully transferable.

The inclusion of direct quotations by participants provides transparency in terms of data collection and analysis, as well as adding to a detailed description of their experiences. Thick, rich descriptions contribute to authenticity as it allows for different participant opinions to be heard.

3.6.3 Dependability

As dependability in qualitative research can be compared to reliability in quantitative research (179), the following strategies were employed to contribute to the consistency of data:

3.6.3.1 Independent scrutiny of data

The researcher's supervisors reviewed themes that evolved from data analysis to ensure accuracy of analysis. Both supervisors are qualified occupational therapists and experienced researchers.

3.6.3.2 Data saturation

Data saturation was reached after 11 interviews. Based on the "saturation grid" described by Brod,Tesler & Christensen (188) which the researcher used, in which emerging themes are written down horizontally and names of participants vertically, it became clear that no new information emerged.

3.7 Ethical considerations

3.7.1 Approvals and permission obtained

The Faculty of Health Sciences' Graduate Studies Committee approved the research protocol of this study. Ethical clearance was obtained from the Ethics Committee for Research on Human Subjects at the University of the Witwatersrand, ethics number M061007 (Appendix C). Permission has also been obtained from the Medical Director at the Private Psychiatric Hospital to include MHCUs who have been re-admitted to the hospital in this study (Appendix D).

Consent forms (Appendix E, Appendix F) and information sheets (Appendix G) were signed once the MHCU agreed to participate. Consent was also gained from the consulting psychiatrist.

3.7.2 Ethical guidelines

The following guidelines were followed to ensure that the study was based on ethical principles:

3.7.2.1 Obtaining informed consent

Flick (189) highlighted that consent should be obtained from participants, granting that they are competent to do so. Participants should be adequately informed about the research study and the implications that it holds for them. Consent should be given voluntarily.

The above guidelines were followed in this study, as the purpose of the study and the level of their involvement was explained to MHCUs. They were informed that participation was voluntary and that they could withdraw from the study at any time. Participants received an information sheet and consent forms that they signed (for participation and for audio-taping).

3.7.2.2 Avoiding harm in collecting data

When interviewing participants about their experiences of ill health, they may be confronted with the reality of their illness and the negative consequences that it might hold for them. Consideration for their emotional wellbeing was therefore given during the data collection phase of the study.

In this study, participants were encouraged to reflect upon the difficulties that they had experienced after discharge. The researcher was aware that this reflection could lead to emotional distress. Additional emotional support was available to participants who struggled to deal with the emotional content of the interviews; in inviting them for a follow-up appointment should they identify the need. The consulting psychiatrist was informed of the MHCU's participation in the study and their permission obtained, which created the opportunity for reflection in subsequent therapy sessions.

3.7.2.3 Maintaining confidentiality

Confidentiality was maintained on records as their names or initials did not refer to participants during this study. A unique coding system was used to identify participants. The name of the hospital has been withheld and was referred to as a "Private Psychiatric Hospital" in this study. Written records referring to participants (e.g. their consent letters) as well as an external hard drive (containing the recorded interviews and transcripts), were kept in a locked facility. Sensitive data on the researcher's computer were protected with a password. Written and recorded data were destroyed after completion of the study.

3.7.2.4 Avoiding deception of participants

According to Neuman (190)(p229) "deception occurs when the researcher intentionally misleads subjects by way of verbal or written instructions, the actions of other people or certain aspects of the setting". De Vos et al. (179) took a stance

against deception of participants and further advised that deception that occurred unwittingly, should be discussed with participants during a debriefing interview.

In this study, no form of deceit was employed as participants were informed of the purpose of the study and their level of participation was explained. Interviews were recorded with their permission.

3.8 Conclusion

The use of a qualitative descriptive design to explore the challenges experienced by MHCUs that could lead to their readmission as well as their perceived value of support groups, has been discussed in this chapter. The research procedure that was followed was outlined. Strategies to ensure validation as well as ethical considerations were discussed.

The next chapter will provide an overview of the findings of this study.

CHAPTER 4
PRESENTATION OF FINDINGS

4.1 Introduction

In this chapter, findings of the study are presented and MHCUs who participated in the study are introduced. Data were obtained through semi-structured interviews. The data were analysed to answer the first and second research questions respectively. The experiences that participants shared during the interviews that are relevant to the research questions are presented as quotes. All quotes are written in **bold**. Afrikaans quotes have been translated into English. If an interview was conducted in English, only the English quote is provided.

4.2 Demographics of participants

The sample in this study comprised 11 participants who met the inclusion criteria, as saturation was reached after 11 interviews. Qualitative research, by its nature, usually has small sample sizes (191). One participant withdrew from the study and another participant was selected in her place. Eight of the participants were female while three were male. No other demographic data were collected. Participant names have been withheld to ensure confidentiality. Pseudo-names were used instead.

4.3 Findings relating to the first research question

This research question aimed to provide insight into the challenges that MHCUs experienced after discharge that could have contributed to their readmission within six months from discharge.

Three themes emerged as a result of data analysis. Theme one: “Inability to fully benefit from hospitalisation” focused on the fact that participants felt distracted during their first admission and therefore was unable to focus on their recovery. The focus of theme two: “Life was not what I expected it to be after discharge” highlighted the realisation by participants that life after discharge was different to what they had hoped it would be. In theme three: “I did not feel supported after discharge”,

participants reflected on the role that other people played in their lives after discharge.

4.3.1 Theme 1: Inability to fully benefit from hospitalisation

In this theme, participants described not being able to make the most of their time in hospital. They did not feel ready to go home, but felt compelled to leave hospital due to internal and external pressures. Participants also reported that they could not fully benefit from the therapeutic programme during their first admission, which left them feeling ill-prepared for discharge. The meaning units, clusters and sub-themes contributing to theme one are listed in Table 4.1 below:

Table 4.1 Sub-themes, clusters and meaning units of theme one

Theme 1: **Inability to fully benefit from hospitalisation**.		
Sub-themes:	**Clusters:**	**Meaning units:**
Internal pressures leading to discharge.	Feelings of guilt.	Internal struggle due to neglected occupational roles. Comparing yourself to others. Their needs are more important than mine.
External pressures leading to discharge.	Effects of managed healthcare.	Medical aid restricts treatment. Uncertainty regarding availability of funds causes anxiety.
	Family pressures.	Come home, you are not sick. Come home, we struggle without you. Come home, a psychiatric hospital is a dangerous place.
Inability to fully benefit from the therapeutic programme.	Inability to concentrate and retain information.	Side-effects of medication. You feel confused after ECT. You cannot concentrate.
	It takes time to adapt to a new environment.	Your first admission is overwhelming. Meeting new people is scary. Poor self-esteem holds you back.
	You do not have enough insight yet.	You do not realise what your needs are. You are admitted because others say so.

4.3.1.1 Internal pressures leading to discharge

Participants described an internal emotional struggle that diverted their attention from their treatment. On the one hand, participants acknowledged the need for hospitalisation while on the other hand they felt compelled to be discharged before adequate treatment gains have been made. Pressure to be discharged was precipitated by feelings of guilt, as participants could not fulfil responsibilities associated with their roles. Participant accounts portrayed a sense of urgency to be discharged, which was also attributed to an under-estimation of their treatment needs.

4.3.1.1.1 Feelings of guilt

Although the factors resulting in feelings of guilt varied in nature, they had the same effect namely compelling participants to be discharged before they were ready.

Firstly, participants were aware that they were not fulfilling their occupational roles at home and at work which resulted in feelings of guilt. Other people had to take over their responsibilities due to their admission in hospital. Being in hospital, removed participants from their everyday routines which could be perceived as a stressor in itself:

Rene: "Die skuldgevoel omdat jy hier sit... jou werkskollegas moet basies vir jou instaan, ja en die man moet al jou huistake vir jou oorneem."

Rene: "The guilt feeling because you are here... your work colleagues have to stand in for your work, yes and your husband has to take over all your domestic duties."

Although Stefan was reluctant to elaborate throughout the interview, he acknowledged that he felt pressurised to be discharged during his first admission due to his responsibilities at home:

Stefan: "My verpligtinge by die huis..."

Stefan: "My commitments at home..."

Furthermore, some participants under-estimated their own treatment needs which resulted in feelings of guilt because they were still in hospital.

Liezel described how she compared herself with some of the more acutely ill MHCUs. She came to the conclusion that she ought to be discharged as she seemed well and recovered compared to them, disregarding the fact that MHCUs are at different stages of recovery during hospitalisation.

Liezel: "Jy kyk na die ander en hulle lyk baie sieker as jy dan besef jy 'maar ek is gesond', maar jy is nie gesond nie."

Liezel: "You look at the others and they seem a lot more ill than you and you realise 'but I am fine', but actually you are not."

Furthermore, all but one of the participants fulfilled the role of spouse and/or parent and stepping out of these caring roles was experienced as abandoning their loved ones. As seen in the following quote by Mari, the needs of others were placed above her own treatment needs:

Marie: "Die lewe gaan aan en ek moet daar wees, mense het my nodig. So jammer ek moet loop... So obviously was dit nie genoeg tyd nie."

Marie: "Life goes on and I have to be there, people need me. So sorry, I have to go... So obviously it wasn't enough time."

In conclusion, participants wanted to be discharged due to their guilt feelings related to being in hospital. They were aware that they neglected their responsibilities at home and at work while they were in hospital. Furthermore, participants under-estimated their own treatment needs which resulted in subjective pressure to be discharged.

4.3.1.2 External pressures leading to discharge

Pressures were not only experienced as being internal in nature, but participants reported some external pressures as well. These pressures contributed to them being discharged, despite not feeling ready.

Participants reported two external factors that contributed to the pressure of having to be discharged, despite not feeling ready. These were described as the effects of managed healthcare, as well as pressure applied by family members to come home.

4.3.1.2.1 Effects of managed healthcare

Five of the participants' hospitalisation was negatively impacted by medical aid restrictions and three had to leave hospital because their medical aid benefits were depleted. Their length of hospital admission was not determined by symptom improvement or resolution, but by the number of days that their medical scheme allowed for psychiatric hospitalisation per year.

Various participants cited the reason for their premature discharge during their first admission as the medical aid funding which was depleted:

Elsabe: "Die medies was uitgeput gewees so volgens die medies kon ek nie nog gebly het nie."

Elsabe: "The medical aid was depleted so according to the medical aid I could not have stayed longer."

Stefan: "Mediese fonds."

Stefan: "Medical aid."

Oscar: "My mediese fonds, hulle het gesê, ja dit gaan uitgeput wees, so toe moes ek huis toe gaan."

Oscar: "My medical aid, they said, yes that it was going to be depleted, so therefore I had to go home."

Participants reported that they would have liked to be admitted to hospital for a longer period as they were aware that they have not recovered sufficiently. However, the depletion of their medical aid resulted in participants having to be discharged before adequate treatment gains had been made.

In addition to the external pressure of depleted medical aid funding, uncertainty about the amount of funding that was available was also experienced as a burden. Rene described the use of unfamiliar terminology by staff e.g. PMB (Prescribed Minimum Benefits) as confusing. This led to uncertainty as to how much funding still was available which resulted in anxiety. As seen in the quote below, it contributed to her decision to be discharged:

Rene: “Hulle het gepraat van PMB, dit het my benoud gemaak omdat ek nie geweet het van al hierdie goed nie.... So ek was bang vir dit, ek het nie geweet waarvan praat hulle nie en toe wou ek eerder huis toe gaan voordat ek hierdie hierdie rekening kry.”

Rene: “They spoke about PMB, it made me feel anxious because I didn’t know about all these things... So I was afraid of it, I didn’t know what they were talking about and I rather wanted to go home before I received this account.”

4.3.1.2.2 Family pressures

The second external pressure that led to premature discharge was related to family. Some participants spoke of the pressure that they felt from their family members to be discharged.

For many of the families involved, having a loved one admitted to a Private Psychiatric Hospital was their first encounter with mental health care. Families, just as MHCUs, felt overwhelmed by this experience. They were ill-informed about psychiatric treatment and had a misguided image of what happens in hospital due to a lack of insight. This will be further explored in 4.3.3.2 (Obstacles in seeking and providing support) as a lack of insight greatly influenced the quality of support offered to participants after discharge.

As family members had limited knowledge about MDD as disorder, they did not acknowledge the MHCU’s need for hospitalisation as described by Liezel:

Liezel: “Daar is elke dag vir my gesê daar is niks verkeerd met jou nie, jy kan maar huis toe kom. En ek het ook gedog nee OK dan is daar niks verkeerd met my nie, so ek gaan huis toe.”

Liezel: “I have been told every day that there is nothing wrong with me, I can just as well go home. So I thought no OK then there couldn’t be anything wrong with me, so I am going home.”

While Rene’s husband feared for her life and wellbeing while she was admitted and therefore wanted her to be discharged, as seen in the quote below:

Rene: “Die druk van die huis af om huis toe te kom, want hy was baie bekommerd … Want hy het ook nie geweet wat hier aangaan nie. Hy het gedink hulle stop jou vol pille en niemand weet wat doen hulle met jou nie.”

Rene: “The pressure from home to come home, because he was very worried... Because he didn’t know what happens in here. He thought that they shoved you full of pills and no one knows what they do with you.”

In addition to limited insight, family members’ pressure for participants to be discharged was also influenced by their own unmet needs. Many of participants’ responsibilities had to be taken over by family members during their admission. Already lacking insight, they experienced participants’ admission to hospital as being on a “holiday” while they had to struggle to manage tasks at home as seen in the following two quotes:

Alvene: “Jy is met vakansie, dis hoe hulle dit sien en hulle moet aangaan... ek dink dis ook hoekom ek die eerste keer te gou huis toe wou gaan.”

Alvene: “You are on holiday, that is how they see it and they have to go on... I think that is also why I wanted to go home too soon the first time.”

Liezel: “Hier en daar het daar verwyte geval want hulle moes alleen regkom terwyl ek vir ‘n week in ‘n hospitaal was.”

Liezel: “They dropped recriminations here and there that they had to cope by themselves while I spent a week in hospital.”

However, Elsabe noted it was not only negative feedback from family members that placed pressure on participants to be discharged. Her family’s continued requests for her to return home because she was missed were also experienced as pressure:

Elsabe: “Dis die heeltyd ‘ons verlang’ en ‘hoe gaan dit met jou’ en ‘wanneer kom jy huis toe’ en ek was nie reg gewees om huis toe te gaan nie, verstaan jy?”

Elsabe: “It’s ‘we miss you’ and ‘how are you doing’ and ‘when are you coming home’ and I wasn’t ready to go home, do you understand?”

Participants found it difficult to deal with the reaction of their family members towards hospitalisation. Whether it was that they were not seen as ill enough to warrant hospitalisation, or that family members missed them and tried to convince them to come home, the pressure that these comments created led to premature discharge.

In conclusion, some of the challenges that participants faced that contributed to their re-admission, started even before discharge from hospital. External pressures, like depleted medical scheme funding as well as pressures applied by family members, lead to participants being discharged before they felt ready for it.

4.3.1.3 Inability to fully benefit from the therapeutic programme

In addition to internal and external pressures that diverted participants' ability to focus on their recovery whilst in hospital, it became clear that they were unable to fully benefit from the occupational therapy treatment programme. Participants were able to reflect on these challenges during their second admission and at the time of the interview for this study, they were able to contrast their first and second admission with one another. The inability to fully benefit from the therapeutic programme contributed to the experience of being ill-prepared to face the challenges following discharge.

Three reasons emerged for participants' inability to use their first admission to their full benefit. These were: Inability to concentrate and retain information, difficulty adapting to the hospital environment and limited insight during their first hospital admission.

4.3.1.3.1 Inability to concentrate and retain information

Participants' ability to concentrate was impaired which affected their ability to fully participate in occupational therapy group sessions and absorb information.

Many participants only started anti-depressant medication when they were first admitted. They had to adapt to the influence of newly prescribed medication or to changes in their usual dosage, which resulted in the experience of side-effects and leaving some participants feeling unwell as is described by Rene:

Rene: "Ek was nie op die regte pille nie en dit het nie vir my gewerk nie… ek het verskriklik baie newe-effekte gehad."

Rene: "I didn't use the right tablets and it didn't work for me... I really suffered from side-effects."

Elsabe not only reflected on her own experience of being medicated, but also on her perception of the influence of medication on other MHCUs in the hospital:

Elsabe: "Baie van ons is op medikasie, baie van hierdie ouens loop soos zombies hier rond so jy neem buitendien nie in nie."

Elsabe: "Many of us are on medication, many of the guys here walk around like zombies so you can't absorb any information in anyway."

Another factor that negatively influenced the ability to retain information is poor concentration as a symptom of depression. Sarie was keen to attend groups, but acknowledged how difficult it was to recall any information after attending the psycho-educational groups:

Sarie: "Weet jy ek wil graag hierdie groepe ook bywoon. Ek het nou al een keer probeer maar as ek uitstap het ek alles vergeet."

Sarie: "Do you know I would like to attend these groups as well. I did try once, but as soon as I walk out of the door, I have forgotten everything."

Although Elsabe was the only participant who received ECT during admission, it had a profound influence on her ability to benefit from the occupational therapy programme. She reported feeling in a daze after each ECT session which impaired her ability to absorb information:

Elsabe: "Ek het deur skokterapie gegaan en deur al die sessie gegaan en helfte van die tyd het ek nie geweet wat aangaan nie. Uhm die sessies kon ek nie inneem nie, ek kon nie daarby baatvind nie."

Elsabe: "I went through shock therapy and through all the sessions and I didn't know what was going on half of the time. Uhm I couldn't absorb the sessions, I couldn't benefit from it."

Poor concentration due to the effect of medication, as a symptom of depression or due to the effects of ECT made it difficult for participants to benefit from therapeutic sessions.

4.3.1.3.2 It takes time to adapt to a new environment

Another factor that seemed to prevent participants from making the most of their first admission was the fact that it took time to adapt to a new environment. Many participants felt emotionally overwhelmed as it was their first admission to a psychiatric clinic and they were unsure what to expect. This uncertainty, coupled with being in a distressed emotional state inherently related to the acute phase of psychiatric illness, made their first admission particularly stressful:

Elsabe: "My heel eerste ervaring wat ek gehad het was maar sleg gewees toe ek hier aangekom het... ek was absoluut in 'n toestand... alles was vir my erg gewees."

Elsabe: "My first experience when I arrived was quite negative... I was absolutely in a state... everything was terrible for me."

Neels: "Die eerste keer was dit vir my rof, ek het baie gehuil."

Neels: "The first time was rough, I cried a lot".

Although MHCUs were encouraged to attend occupational therapy group sessions immediately after admission, participants reported that the first few days were spent with their focus on other issues.

Neels acknowledged that it took him a few days before he settled down and felt ready to participate:

Neels: "Dit het my twee of drie dae gevat voor ek begin aanpas het."

Neels: "It took me two or three days before I started adapting."

While Liezel reflected on the primary need to rest during the first few days which witheld her from participating in the group therapy programme:

Liezel: "Kyk jou eerste paar dae rus jy."

Liezel: "See you rest for the first few days."

One reason that contributed to participants' sense of feeling overwhelmed was being confronted with strangers in the hospital setting. It took time to get to know fellow

MHCUs and to feel comfortable enough to allow participation in group therapy sessions:

Elsabe: “Ek het niemand geken nie.”

Elsabe: “I didn’t know anyone.”

Liezel: “Ek hou nie van mense om my nie, ek’s ‘n alleen mens.”

Liezel: “I don’t like having people around me, I’m a loner.”

Neels: “... die mense en goed want ek was so scary gewees.”

Neels: “... the people and stuff because I was so scared.”

Another underlying factor that acted as an initial barrier to participation was a lack of self-esteem. Participants described how a lack of confidence prevented them from reaching out to other MHCUs and exploring the facilities that the hospital had to offer, resulting in missed opportunities for participation and meaningful interaction.

Liezel was painfully aware of her lack of self-confidence and repeatedly referred to it as a barrier to her recovery throughout the interview. As she described her initial hesitation to participate in the occupational therapy programme she was very clear about the cause:

Liezel: “… omrede ‘n mens ‘n swak selfbeeld het.”

Liezel: “… because one has poor self-esteem.”

Neels did not explicitly cite low self-esteem as reason for not participating initially. However, as he lacked the courage to enquire about activities, he delayed participation and was therefore not able to make the most of his first admission:

Neels: “Want ek het nie geweet waar dit is nie en ek wou vir niemand vra waar dit is nie... ek het net daar in die kamer gebly.”

Neels: “I didn’t know where it was and I didn’t want to ask anyone where it was... I just stayed there in the room.”

Therefore, by the time that participants have settled down in the hospital setting and felt confident enough to participate, they have lost valuable treatment time during their admission period, which only lasted two weeks on average.

4.3.1.3.3 You do not have enough insight yet

A lack of insight during their first admission was another factor that made it difficult for participants to make the most of their time in hospital. The effects of limited insight presented itself in the following two ways: choosing which occupational therapy groups to attend and the degree to which responsibility for own recovery was taken.

Mental Health Care Users were encouraged to attend all occupational therapy groupwork sessions during their admission. Although all of the topics addressed during thematic groups had a focus on coping strategies necessary to address disrupted occupations associated with MDD, participants came to the conclusion that some topics were more relevant to their specific treatment needs than others. However, this insight only developed after their first discharge when participants were confronted with challenging situations at home and were then able to identify gaps in their knowledge regarding specific coping skills. They were more accurately aware of their treatment needs during their readmission and felt better able to choose and attend groups in a goal-directed manner. Therefore, participants lacked the insight during their first admission to make a well-informed decision about which group sessions to choose.

As seen in the quotes below, Neels and Liezel reflected on the different choices that they made regarding group attendance when comparing their first and second admission:

Neels: “Hierdie keer doen ek net die wat my, ek sal nie se betrekking het op my nie maar die wat ek voel ek baie nodig het soos die angs en die depressie en daai en die konflik hantering en daai, dit het ek laas als gedoen.”

Neels: “I only do the ones, I wouldn’t say that concern me, but those that I feel I need like anxiety and depression and those and the conflict management and those, I did the previous time.”

Liezel: "… ek wil werk aan my selfbeeld en ek wil 'n sterker mens hier uitkom."

Liezel: "… I want to work on my self-esteem and I want to be a stronger person when I leave."

Secondly, some participants acknowledged that they did not take responsibility for their admission and recovery during their first admission. Participants lacked insight into the severity of their depression as well the degree to which their daily occupations were disrupted by the disorder. Therefore, they did not acknowledge the need to be hospitalised. Their employer or family members advised them to be admitted due to concerns about their mental wellbeing that was clearly noticeable to others. They participated in the occupational therapy programme because it was expected of them but lacked the insight to realise that they had to take responsibility for their own recovery.

Participants described a renewed sense of purpose to make the most of their readmission. It was only with hindsight that participants realised that recovery was their own responsibility and this newly developed insight motivated them to approach their readmission differently. Benefitting fully from hospital admission proved to be difficult, if the recovery process was driven by an external locus of control.

Elsabe reflected on this process of developing insight. She progressed from purely adhering to expectations of others to acknowledging the need to take responsibility:

Elsabe: "Dit was vir my 'n kwessie van die eerste keer uhm al die verwagtinge… dit was die beste plek om na toe te gaan verstaan jy want jy cope nie en dit gaan baie sleg met jou en als en als... en die tweede keer was ek alleen, ek het myself laat opneem en ek was gedermineerd om nou hier uit te stap."

Elsabe: "It was an issue of all the expectations during the first time... it was the best place to go to, do you understand, because you don't cope and you are in a bad state... I was alone with the second time, I had myself admitted and I was determined to walk out of here."

While Elsabe's relatives plays a significant role in convincing her to be admitted, Neels's employer set an ultimatum which left him with no other choice than to be

admitted. However, he also developed enough insight to now acknowledge his own responsibility:

Neels: "Die vorige keer het die werk gesê ek kan nie meer so aangaan nie, ek moet (opgeneem word). Die keer was dit uit my eie uit... ek wil terugkom en hierdie keer wil ek 'n sukses daarvan maak."

Neels: "The work said that I couldn't go on like that anymore the previous time, I had to (be admitted). This time it was out of my own free will...I wanted to come back and this time I want to make a success out of it."

In conclusion, the inability to retain information that was shared during psycho-educational groups as well as the loss of valuable treatment time due to difficulties in adapting to the hospital environment prevented participants to fully benefit from the occupational therapy treatment programme. Furthermore, participants did not have sufficient insight to identify their own treatment needs or to realise that recovery was primarily their own responsibility. Participants realised that they weren't able to make the most of their time during their first admission and viewed re-admission as a second chance. All 11 participants agreed that they gained more from their second admission than from their first.

4.3.1.4 Conclusion of theme one

The presence of various internal and external pressures, as well as participants' inability to benefit fully from the therapeutic programme, led to the experience of not feeling ready for discharge. These factors were experienced as challenges, which contributed to their re-admission. The first theme is illustrated in the following diagram:

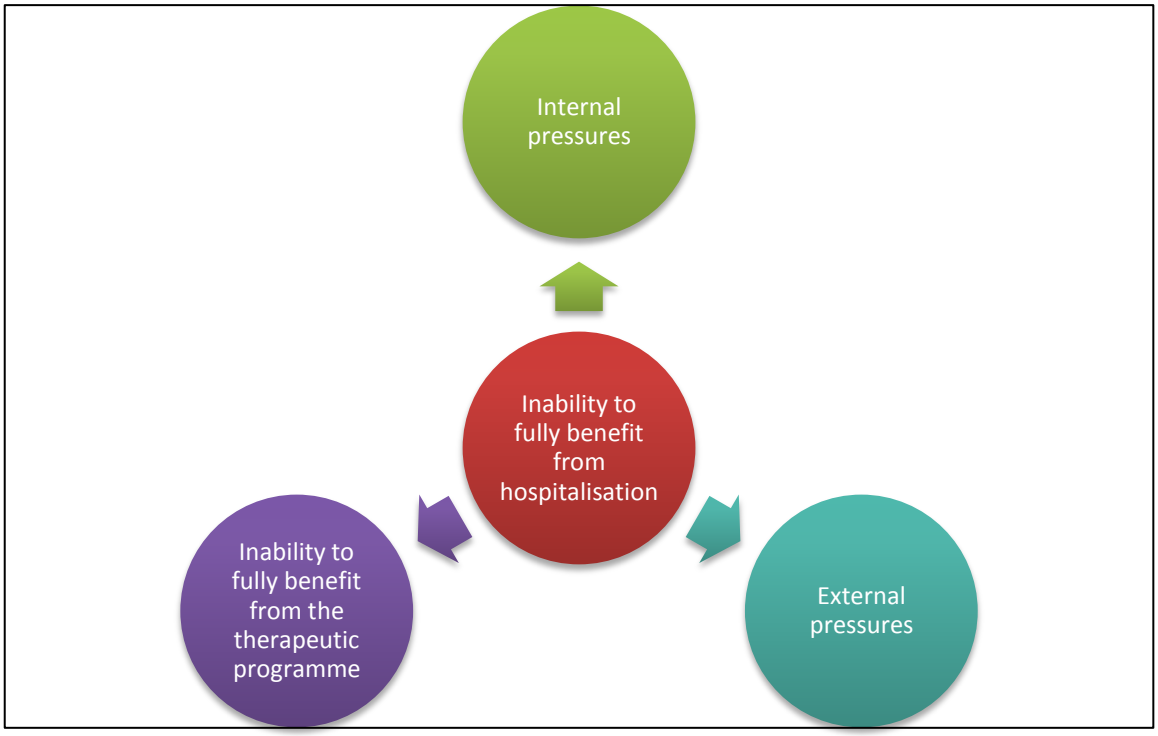


Figure 4.1 Factors contributing to the inability to fully benefit from hospitalisation.

4.3.2 Theme 2: Life was not what I expected it to be after discharge

In this theme, participants described an experience of disillusionment as life was not what they anticipated it to be after discharge.

Participants found it challenging to return to the same life that they had left behind before admission. Furthermore, they described a stark contrast between the ways that they have experienced life in hospital compared to what life was like outside of the hospital. Implementing newly acquired coping skills in order to deal with stressors proved more difficult than expected. The challenge of coming to terms with the reality of life after discharge was intensified by the presence of residual and re-emerging symptoms of depression. The meaning units, clusters and sub-themes contributing to theme two are listed in Table 4.2 below:

Table 4.2 Sub-themes, clusters and meaning units of theme two

Theme 2: **Life was not what I expected it to be after discharge**.		
Sub-themes:	**Clusters:**	**Meaning units:**
Life is still the same.	I expected much more...	I felt disappointed. Life after discharge was a rude awakening.
	I am still the same.	I expected a brand new me. I still struggled.
	People are still the same.	I was still treated badly. I was the only one who changed.
	Situations are still the same.	Problems remain problems. Your absence makes things worse. Medication is a help but not a cure.
	Being home brings back the hurt.	You realise that death is irrevocable. Being at home continually reminds of your loss.
Life “inside the hospital” is different to life “outside”.	Social interaction versus isolation.	It is easy getting on with people in hospital. Everyone is understanding. Even fleeting social contact is appreciated. We are all in the same boat. We encourage one another. You feel isolated at home. You miss the crowd. You feel different to people in everyday life. You feel unworthy of their interaction.
	Feeling protected versus feeling vulnerable.	Being in hospital is like being in a retreat. The outside world cannot hurt you in hospital. Boundaries are enforced on your behalf. There is always someone to support you in hospital. The hospital becomes homely. The world is a harsh place. I felt unsafe.
	Participating in structured activities versus not making effective use of your time.	Group attendance is helpful. Activity participation lifts your mood. Idleness is demotivating. Activity participation requires time.

	It is harder to apply coping skills than I thought.	Hearing it is easy, doing it is difficult. You cannot apply new skills because you cannot remember what you have learnt. Poor problem-solving results in poor coping.
You struggle to implement coping skills and deal with stressors.	Feeling overwhelmed when faced with stressors.	Being thrown back into reality. Everyone else seems to cope but I don't. Traumatic events set you back. Constant stress at home becomes too much to bear.
	Being faced with lingering and re-appearing symptoms of depression.	Being discharged does not mean that you are not depressed anymore. Depression steals your motivation. You do not care about anything.

4.3.2.1 Life is still the same

This sub-theme captured the immense disappointment that participants experienced when they came to the realisation that life did not magically change after discharge, despite hoping for the contrary.

Participants felt disillusioned as the reality of everyday-life dawned upon them. Little remained of the hopeful sense of anticipation with which they left hospital. Their disappointment was described as "I expected much more..." They expressed the realisation that "I am still the same" indicating that changes within themselves were not sustained. They felt "people are still the same" indicating that significant others did not undergo the same growth process as they did, "problems are still problems" indicating that some problems remained and were yet to be confronted and "being home brings back the hurt" indicating that the pain associated with the loss of a loved one is ever-present.

4.3.2.1.1 I expected much more...

Participants left the hospital upon discharge with a strong conviction that they had completely recovered. In an attempt to generalise the personal growth that they underwent in some aspects of their occupational functioning, they held high expectations for improved functioning in all occupational areas. Furthermore, they

expected improvement not only in themselves but also in their significant others. As depressive symptoms subsided and hope was instilled during occupational therapy group sessions, participants created an optimistic picture in their minds of what they thought life would be like. Their expectations were not met and proved to be unrealistic. Participants' immense disappointment became evident in the following quotes:

Stefan: "Dis 'n hengse, dis 'n verskriklike ontnugtering."

Stefan: "It is a huge, it is a terrible disillusionment."

Marie: "Ek het nie geweet wat wag vir my nie. Of besef wat wag vir my nie."

Marie: "I did not know what waited for me. Or realised what waited for me."

Elna: "...ek het meer verwag die eerste keer toe ek huis toe gegaan het, as wat ek gekry het."

Elna: "...I expected more than what I got when I went home the first time."

4.3.2.1.2 I am still the same

Participants expressed disappointment when they were confronted with themselves after discharge. As they have experienced emotional growth in hospital, they assumed that negative thought patterns have been changed, newly learnt skills had been internalized and that their improved mood state would remain. However, it emerged that these positive changes were not sustained after discharge. The realisation that MDD was a chronic disorder was experienced as discouraging:

Sarie: "Dit was so 'n teleurstelling vir my toe ek agterkom eintlik is ek maar nog dieselfde Sarie as wat hier ingekom het."

Sarie: "It was such a disappointment to me when I realised that I actually was the same Sarie that was admitted."

Elna: "... maar tot ek by die huis gekom het toe voel ek ek is ver van reg af."

Elna: "... but when I got home I realised that I was far from okay."

Oscar: "Dat ek anderste sou voel maar ek het nie anderste gevoel nie."

Oscar: “That I would feel differently but I didn’t.”

One of the first challenges that participants had was coming to terms with a more realistic image of themselves and what life was like after discharge.

4.3.2.1.3 People are still the same

Participants were taken aback by the realisation that the outside world didn’t automatically adjust to the growth that they had experienced as individuals. They were confronted with the fact that the only change that they could be assured of was the change that occurred within them. Being treated unkindly by significant others was experienced as a major disappointment. Both Liezel and Elna were caught up in manipulative relationships before admission and anticipated that these relationships would improve. However, they realised that nothing has changed as seen in the quotes below:

Liezel: “Presies dieselfde roetine wat ek gehad het voordat ek opgeneem was hierso. Manipulerende gedrag gehad... alles het maar dieselfde geloop as wat dit was.”

Liezel: “Exactly the same routine that I have had before I was admitted here. Manipulating behaviour… everything went on in the same way as it did.”

Elna: “Ek het verwag dat dinge beter sal werk. Dat mense beter my sal hanteer. Dat my ma my nie meer die swartskaap (sal noem nie).”

Elna: “I expected things to turn out better. That people would treat me beter. That my mom would not refer to me as the black sheep any longer.”

As the following quote by Marie highlighted, participants felt more competent to deal with daily hassles based on the coping skills that they have acquired during hospitalisation. However, they held an unrealistic expectation that friends, family members and co-workers also possessed adequate skills:

Marie: “Ons probeer werk aan hoe om konflik te hanteer en hoe om stress te hanteer en die hele gedoente. Maar wat vir jou buite wag, die mense wat gewoonlik daar is, so ek meen niks van hulle het verander nie.”

Marie: "We try to work on how to deal with conflict and stress and everything else. But what awaits you outside, the people that are usually there, I mean nothing about them has changed."

Participants felt discouraged when their significant others did not display the same degree of emotional growth and behavioural change as they themselves had undergone during hospitalisation. They came to the conclusion that some relationships would remain challenging.

4.3.2.1.4 Situations are still the same

In addition to relationship difficulties that were experienced as setbacks after discharge, participants also reported that situational stressors remained the same. They were still faced with the same problems that they had encountered before admission. This took them by surprise as they expected all of their problems to be solved at the time of discharge. Although problematic personal situations were addressed during hospitalisation through group attendance and individual sessions with staff, these still required attention after discharge. However, participants were taken aback by the amount of problem-solving that was necessary after discharge:

Sarie: "...ek het huis toe gegaan en gedink 'oh well ek is OK, ek het nou nie meer probleme nie', en dit was nooit so nie."

Sarie: "I went home and thought 'Oh well, I am OK, I don't have any problems anymore' but it wasn't like that."

Marie: "So dis nie asof jou stresfaktore verdwyn terwyl jy hier is nie, dit is nog daar."

Marie: "So it is not as if your stress factors disappear while you are here, it is still there."

Instead of encountering an improved situation after discharge, the opposite held true for some participants. The disappointment of returning to an unchanged problematic situation after discharge was intensified for Stefan, as he felt that his absence complicated matters even more than before his admission:

Stefan: “Niks het verander nie… inteendeel, dis net ‘n bietjie meer intenser, omdat jy nie meer daar was nie.”

Stefan: “Nothing changed... as a matter of fact; it’s a little bit more intense, because you haven’t been there.”

Rene acknowledged that her prescribed medication had a calming effect on her and therefore enabled her to cope more effectively with situational stressors. However, her problems remained a challenge despite the helpful effect of medication:

Rene: “Dis nie regtig asof jou probleme weg is nie. Wat dit miskien beter maak is die die pilletjies maak dat jy rustig is oor alles maar dis nie weg nie.”

Rene: “It is not as though your problems are gone. Perhaps the tablets help that you are more relaxed about everything, but it is not gone.”

Participants were discouraged when they encountered problems after discharge as it was not in line with how they expected life to be. The emotional impact of discouragement served as an obstacle in their recovery process and subsequently contributed to their relapse and readmission to hospital.

4.3.2.1.5 Being home brings back the hurt

Lastly, returning to their home environments reminded two participants of a life-changing loss that they have suffered. Both Elsabe and Neels had lost a child prior to hospitalisation. Being away from home allowed them to shift their attention from their hurt, thus allowing them to become more engaged with the rhythm of life in hospital. They were not continually reminded of their loss while they were away from home. However, they were confronted with painful memories upon their return home. This reminded them of the hurt that triggered their admission and that had not yet been completely resolved.

The emptiness that she felt at home was particularly confrontational for Elsabe, to the extent that her child’s death was almost tangible:

Elsabe: “Toe ek by die huis gekom het was dit vir my baie sleg gewees, ek het vir Pieta verwag, ek het verwag Pietertjie moet by die huis wees... ek het by die

leë huis ingestap en my kind was nie daar gewees nie. Dit was regtig dood, verstaan jy?"

Elsabe: "It was really terrible arriving at home, I expected Pieta, I expected that Pietertjie should be at home... I walked into the empty house and my child wasn't there. It was really dead, do you understand?"

Neels continued to receive telephone calls intended for his son from people that were unaware of his death. Being reminded of the reality of his son's death was experienced as a major setback for him:

Neels: "Mense wat bel, na ses sewe maande wat hy al oorlede en begrawe is, dan bel hulle nogsteeds en wil met hom praat en goed. En dit upset my so... dit is bad memories wat terugkom."

Neels: "People who phone, after six seven months after he died and was buried, they still phone and want to talk to him and stuff. And that really upsets me... it brings back bad memories."

The accounts of Elsabe and Neels showed that being in hospital essentially interrupted their grieving process by providing emotional respite in a more neutral environment. Having to face the reality of their loss once they were back at home was very difficult.

In conclusion, participants were confronted with the realisation that their lives went on in much the same way as it had before admission. The essence of their experience was described as disappointment. People and situations remained the same. Returning home also made them confront the losses once again that they had suffered prior to admission. Participants came to the conclusion that they held unrealistic expectations about life after discharge which resulted in feelings of discouragement. Being at home proved to be more challenging that they had anticipated.

4.3.2.2 Life "inside the hospital" is different to life "outside"

This sub-theme describes the contrast between participants' experience of life in hospital as opposed to their experience of life outside hospital. This contrast was so significant that it made it difficult for participants to adapt to life at home and served

as an obstacle in their recovery process. Furthermore, the disparity highlighted the fact that life after discharge did not resemble the life that participants anticipated it to be.

Participants described the hospital as a place which facilitated social interaction, which provided support and helped them to occupy their time in a meaningful manner, by introducing them to various activities. These aspects of their hospital treatment facilitated their recovery. It contrasted with their experiences at home and in their communities, which was described as unconducive for their recovery. Participants' contradictory experiences will now be discussed:

4.3.2.2.1 Social interaction versus isolation

Participants valued the opportunity for social interaction that the hospital environment offered to them. They experienced a sense of belonging among people who they perceived as understanding of their difficulties. Participants described a feeling of connectedness, even when contact was superficial and fleeting:

Daphne: "Jy weet want jy het baie kontak, sosiale kontak, met party van jou mede-pasiente, al is dit ook net hallo en koebaai, maar dis mense om jou."

Daphne: "You have lots of social contact you know, with some of your fellow patients, even if it is just hello and goodbye, but it's people around you."

Andrea: "Knowing that you're all in the same boat, which is really important."

One participant, who was severely depressed, reflected upon the confidence-building aspect of social interaction. When large groups (including occupational therapy groupwork sessions) were experienced as daunting, establishing social contact with one's roommate served as the first building block to an improved self-esteem, as seen in Andrea's quote below:

Andrea: "One thing was that I had a very nice ward mate, you know, and she uhm, we got on really well. I thought, you know, if I got on so well with her, then it wouldn't be a problem outside."

Apart from a purely social function, interaction with other MHCUs also served as a source of encouragement and knowledge about coping with depression. Stefan particularly valued the learning aspect of social interaction:

Stefan: "... mens leer eintlik meer by die mense met wie jy gesels oor wat aangaan as in die klasse."

Stefan: "... you actually learn more from the people whom you talk to here than in the classes."

The positive experiences of social interaction in hospital as described above contrasted starkly with participants' experiences at home. Participant accounts portray a desperate sense of isolation. They found it difficult to re-connect with or establish social contacts outside of hospital. Some participants described their isolation in a physical sense and did not encounter other people for prolonged periods, while other participants described an emotional isolation as they found it difficult to relate to other people. In essence, participants missed the experience of connectedness that they had experience in hospital, as seen in the quotes below:

Oscar: "As jy 'n bietjie af voel die dag, jy kan nie met iemand gesels daaroor nie want jy is alleen by die huis."

Oscar: "You have no one to talk to if you feel a bit down the day, because you're all alone at home."

Liezel: "... by die huis kan jy met niemand praat nie."

Liezel: "... you can't speak to anyone at home."

Andrea: "... the crowd, you miss that."

Oscar's and Andrea's description of loneliness above can be ascribed to the fact that they did not return to work or other structured activities after discharge and spent prolonged period alone at home. However, Neels and Marie did return to work but found it difficult to relate to their colleagues. They described feeling detached from the group despite being surrounded by other people:

Neels: "... by die werk was dit net so alleen."

Neels: "... it was so lonely at work."

Marie: "... ewe skielik het ek net gevoel weet jy ek pas nie hier in nie, ek hoort nie hier nie."

Marie: "... all of a sudden I just had this feeling that I did't fit in here, I don't belong here."

Oscar: "... ek nie eers wil teruggaan werk toe nie, die politiek daar was te erg."

Oscar: "... I don't even want to go back to work, the politics there were terrible."

Sarie described an experience of physical and emotional isolation, as her freedom of movement was restricted due to an abusive marital relationship:

Sarie: "Leon sluit my hek as hy werk toe gaan. Ek mag glad nie... vir my kinders gaan kuier nie."

Sarie: "Leon locks my gate when he goes to work. I am not allowed... to visit my children."

While participants valued the confidence-building aspect of social interaction in hospital, their newly found confidence was diminished when they were faced with groups of people after discharge. As Andrea and Marie described in the quotes below, they doubted their own self-worth:

Andrea: "In making social contact with others... that was hard... To go to church, I felt I wasn't good enough."

Marie: "Ek is dom, ek is stupid en ek is lelik. Ek het so geïntimideer gevoel deur almal wat daar was."

Marie: "I am an idiot, I am stupid and I am ugly. I felt so intimidated by everyone there."

Poor self-confidence, as well being physically and emotionally detached from other people, contributed to feelings of loneliness, which was experienced as an obstacle in the process of recovering from MDD.

4.3.2.2.2 Feeling protected versus feeling vulnerable

In addition to fulfilling a facilitatory function in terms of social interaction, the hospital also provided a place of safety. Participants described the hospital as a sanctuary, which shielded them from outside threats. Feeling protected contrasted starkly with the experience of vulnerability when being thrown back into the demands of everyday life.

Their psychiatrists, psychologists, occupational therapists, ward staff and other MHCU's supported participants during hospitalisation. Everyone in this environment had their best interests at heart. They were handled delicately as staff and other MHCUs were empathetic to their needs. All of their basic needs were taken care of with the only responsibilities being to attend the occupational therapy programme as well as treatment sessions with other staff. Participants described the hospital as a secluded space removed from the demands of everyday life, where they could focus on their own needs:

Elsabe: "Want hier het jy gevoel jy is in watte. Hier kan die buitewereld jou nie seermaak nie."

Elsabe: "Because here you felt as if you were wrapped in cotton wool. Here the outside world can't hurt you."

Stefan: "Hierdie is eintlik 'n eiland."

Stefan: "This is really an island."

Stressors that precipitated their admission seemed far away. Participant accounts highlighted feelings of protection and safety:

Rene: "Daai veiligheid van hier wees..."

Rene: "That safety of being here..."

Marie: "Hier voel ek veiliger."

Marie: "I feel safer here."

Stefan: "Ek het eintlik baie veilig hier gevoel."

Stefan: “I actually really felt safe here.”

Participants reflected upon various reasons underlying their feelings of protection and nurturing hospital. Rene and Marie valued the instalment of boundaries on their behalf, which they found difficult to do if not supported:

Rene: “... ‘n dag lank het die psigiater vir die susters laat weet ek mag geen besoekers kry nie omdat hulle my ontstel het. Dit het my baie veilig laat voel.”

Rene: “... the psychiatrist informed the nursing staff that I wasn’t allowed to receive any visitors for a whole day because they upset me. It made me feel very safe.”

Marie: “... jy hoef met niemand te praat as jy nie wil nie.”

Marie: “... you don’t have to speak to anyone if you don’t want to.”

Marie valued the absence of stressors which created a feeling of restfulness:

Marie: “Ek dink dis gemaklik... daar’s niks wat ‘n mens opstres nie. Daar is absoluut geen stres nie. Jy kan sessies bywoon en verf... Dis net rustiger.”

Marie: “I think it is comfortable... nothing makes you feel stressed. There is absolutely no stress. You can attend sessions and paint... It is just more relaxed.”

While Neels highlighted the fact that support is always at hand during hospitalisation:

Neels: “Vir my het dit hierso gevoel, ek het dit geassosieer met ‘n motorfiets: as jy hier neerval sal daar altyd iemand wees wat jou optel, so was dit vir my.”

Neels: “Being here felt like, I compared it to a motorbike: if you fall down here there will always be someone to pick you up, it was like that for me.”

Two participants were particularly surprised by the value that they attached to their nurturing experience in hospital. Stefan was astonished that he valued the experience of nurturing to such an extent:

Stefan: “Jy voel baie cosy, eintlik is dit skokkend hoe cosy jy voel.”

Stefan: “You feel really cosy, actually it’s shocking how cosy you feel.”

Similarly, Marie was caught off guard with the degree to which she associated herself with the hospital. As seen in the quote below, she unexpectedly referred to the Private Psychiatric Hospital as her home during a conversation with her psychologist:

Marie: "Ek het vanoggend vir haar gesê, per ongeluk, ek het vir haar gesê ek wil gister 'huis' toe kom..."

Marie: "I told her this morning, by accident, I told her that I wanted to come 'home' yesterday..."

In contrast to the nurturing that participants experienced in hospital, they felt overwhelmed and vulnerable when they were left to face challenges after discharge. They concluded that the outside world was cruel, a place where one felt insecure, as described by Elsabe and Stefan in the quotes below:

Elsabe: "Daarbuite is die wêreld nogsteeds lelik en seer en swaar."

Elsabe: "The world out there is still ugly and painful and difficult."

Stefan: "Dis nie die wonderlike wêreld soos dit hier binne is nie."

Stefan: "It's not a wonderful world like it is in here."

As Daphne had become a victim of a violent crime after discharge, she felt particularly insecure in her own environment:

Daphne: "...ek het nie meer veilig gevoel buite waar ek bly nie."

Daphne: "... I did not feel safe anymore where I live outside."

Feelings of vulnerability after discharge reminded participants of the contrast between life in hospital and everyday-life in society, which they struggled to come to terms with.

4.3.2.2.3 Participating in structured activities versus not making effective use of your time

Another contrast that participants experienced between hospital and home is the absence of meaningful activities after discharge. The occupational therapy

programme provided structured activities during admission, including thematic groups, craft activities and sport sessions. Activity participation provided structure to their day, served as behavioural activation, taught new skills and improved self-confidence.

Participants valued participation in these activities, as seen in the quotes below:

Neels: “Die Arbeidsklasse wat ek gedoen het was vir my wonderlik gewees. Dit het my baie gehelp.”

Neels: “The Occupational classes that I attended were wonderful. It helped me a lot.”

Marie: “Ek dink dit het defnitief my iets geleer. En die sessies dink ek is baie goed.”

Marie: “I think it definitely taught me something. And I think the sessions are very good.”

Two participants emphasised the therapeutic value of activities. They valued the sense of purposeful doing that was fostered by activity participation. As the hospital offered a variety of activities, it also contributed to a sense of control as participants could choose which activities to attend:

Oscar: “Hierso as jy as jy verveeld raak gaan jy na die kunsklas toe of jy woon een van die praatjies by, so jy hou jou besig...”

Oscar: “If you get bored here you can go to the art class or attend one of the talks, so you keep yourself busy...”

Stefan: “Wat my laas baie gehelp het, ons het verskriklik baie volleyball gespeel en die volleyball het my gered hier uit.”

Stefan: “What really helped me a lot last time, we played a lot of volleyball and the volleyball saved me.”

Stefan particularly valued the playfulness associated with sport. He attributed his recovery to the fact that having fun made him feel less guarded which enabled him to

deal with some of his personal difficulties. He subsequently associated activity participation with his recovery:

Stefan: "As mens weer jou kinderlikheid begin uitbring dan begin jou einas saam uitkom, dis makliker om dit oop te maak en te sê ek het 'n probleem."

Stefan: "If you allow your childlike side to emerge then your hurt starts emerging too, it makes it easier to open up and to say that you have a problem."

Although it was expected of participants to take part in some activities during hospitalisation, they had to create an opportunity for pleasurable activities at home. While activity participation broke the downward spiral of MDD and aided recovery, the absence of participation maintained the downward spiral and had a negative effect on well-being. The downward process was initiated when feelings of discouragement resulted in a decline in activity levels at home. Limited participation reduced the opportunity for positive experiences and a sense of accomplishment, which in turn aggravated depressive symptoms. Having too much or too little time on hand for pleasurable activities were both deemed problematic.

Elsabe and Oscar reflected on the effect of too much time and the absence of purposeful activity participation after discharge:

Elsabe: "Ek het met al hierdie leë tyd op my hande gesit en dan het ek net op die bed gaan lê of ek het net op die bank gaan lê en dis verkeerd. Ek kon myself nie motiveer nie."

Elsabe: "I had all of this time on my hands and then I just sat on the bed or lay on the couch and that's wrong. I couldn't motivate myself."

Oscar: "Ek het glad nie die eerste keer enigsins iets in plek gehad nie... Ek het my nie by die huis besig gehou nie."

Oscar: "I didn't have anything in place the first time... I didn't keep myself busy at home."

On the other hand, Marie had too little time and felt that spending time on her own needs was not a priority Participation in a hobby seemed like a luxury in the hustle

and bustle of everyday life. This left her feeling drained and unable to fulfil all her other responsibilities:

Marie: "Want jy weet by die huis is dit te besig. Jy het nie tyd nie, om iets vir jouself te doen nie."

Marie: "It's too busy at home, you know. You don't have time to do anything for yourself."

Participants recognised the value of being occupied in a meaningful manner during hospitalisation. The absence of the opportunity to participate in these activities after discharge had a negative impact on their emotional wellbeing.

In conclusion, participants felt that their life at home contrasted too much with how they experienced life in hospital. It seemed like two different worlds. Social isolation, feelings of vulnerability and limited participation in meaningful activities were experienced as challenges.

4.3.2.3 You struggle to implement coping skills and deal with stressors

In addition to the disappointment of having to face the life with the same problems as before admission and being confronted with how different life outside of hospital was to that which they had grown accustomed to within the hospital, participants reported a third challenge. This sub-theme captured the difficulty participants experienced when trying to implement coping skills and deal with stressors after discharge.

Although various coping skills were discussed during thematic groups, participants seemed to struggle with the carry-over of information and found it difficult to apply skills in the context of their personal life situation. Three factors emerged that contributed to their struggle: The experience that applying newly learnt skills were not so easy to apply in real life as they had thought the experience of feeling emotionally overwhelmed by stressors and the remaining presence of depressive symptoms, which hampered effective coping.

4.3.2.3.1 It was harder to apply coping skills than I thought

Participants were taken aback at how difficult they found it to apply their newly learnt coping skills after discharge. Once again, they experienced that life in hospital

differed greatly from the life outside of hospital. Their reports highlighted that although they benefitted from occupational therapy group sessions during hospitalisation, coping skills were discussed generically within a broad, general context. Applying it within their own personal context appeared to be more challenging than anticipated.

Furthermore, participants did not have the opportunity to put their newly acquired skills into practice before they are discharged. The feasibility of proposed coping mechanisms could therefore only be established after discharge, when they were once again confronted with a challenging situation. In addition, remembering everything that was learnt in hospital proved a challenge. Therefore, a discrepancy emerged between the information and skills discussed in hospital, and how feasible it was to implement these in reality:

Rene: "Wat die sielkundige sê, metodes en tegnieke, om dit te gaan toepas is minder maklik as wat jy dit hier hoor, en dit werk net nie altyd so in die realiteit nie."

Rene: "What the psychologist says, methods and techniques, it's more difficult to apply it than what you hear here, and it doesn't always work like that in reality."

Stefan: "Jy leer dinge, sodra jy daar buite kom, dan vries jy net heeltemal."

Stefan: "You learn things, but as soon as you get out there, you just totally freeze."

Neels: "Ek het steeds 'n hele pak papiere by die huis, ek het dit deurgegaan en probeer toepas, maar ek kon net nie cope nie."

Neels: "I still have a whole pile of notes at home, I went through it and tried to apply it, but I just could not cope."

Sarie's account portrayed a sense of deep discouragement at her inability to implement coping skills and at not being able to solve problems effectively:

Sarie: "Elke keer as ek iets, 'n krisis het, dan kan ek nie soos iemand anders dink aan 'n probleem ag dink aan hoe om die probleem op te los nie. Die eerste

ding wat in my kop opkom is ek voel verskriklik moeg. Dit voel of my hart moeg is...”

Sarie: “Every time that I experience a crisis, I can’t think about a problem like someone else, I mean think about how to solve the problem. The first thing that comes to mind is that I feel extremely tired. It feels as though my heart is tired...”

Participant accounts reflected feelings of frustration as they diligently kept to the strategies that they had decided upon during hospitalisation, but which failed to deliver the desired outcome. They came to the realisation that it was more difficult to apply coping skills than they thought it would be.

4.3.2.3.2 Feeling overwhelmed when faced with stressors

Another factor that prevented participants from coping with stressors effectively was the fact that they felt overwhelmed by the circumstances awaiting them. Participants described how the impact of stressors exceeded whatever coping mechanisms they had at hand.

As seen in the quotes below, participants felt deluged by the situations that awaited them:

Elna: “Ek het ‘n helse skok gekry toe ek by die huis kom.”

Elna: “I was in for a hell of a shock when I got home.”

Rene: “As jy terugkom is dit met ‘n vreeslike slag is jy weer terug in alles...”

Rene: “You get thrown back into everything with a big bang...”

Stefan: “Ek is direk in my krises ingegegooi, direk...”

Stefan: “I was thrown directly into my crisis, directly...”

Although the shared experience of participants revolved around a sense of bewilderment about their stressors, the severity of stressors varied. Whereas some participants felt overwhelmed by minor stressors, other participants were faced with major traumas or abuse. The variety of stressors are described in the quotes below.

Marie felt overwhelmed by her responsibilities of motherhood; although she acknowledged that many other people coped with the same demands:

Marie: "Ek was tot nou toe die enigste een wat vir hulle moes sorg, alles wat hulle aanbetref soos huiswerk ensovoorts... Dit voel party dae asof ek net nie meer kan nie. Ek weet daar is 110, 120 ander mense wat dit ook moet doen, maar ek cope net nie op hierdie stadium daarmee nie. Ek cope net nie op hierdie stadium met enige iets nie."

Marie: "Up till now I was the only one to look after them, all of their needs like homework ectera... It feels as though I can't go on some days. I know that there are 110,120 other people who also have to do it, but I just can't cope with it at this moment. I can't cope with anything at this moment."

While Daphne experienced a traumatic event shortly after discharge:

Daphne: "Ek het binne 'n week, het ek 'n horribale ondervinding gehad met 'n, hulle noem dit 'n slash and grab, tsotsies, wat my een band aan flarde gesny het... Dit was vir my verskriklik traumaties..."

Daphne: "I had a horrible experience within a week they call it a slash and grab, tsotsies, that cut my one tyre to bits... It was terribly traumatic..."

She described the impact of this event as debilitating, as it greatly impaired the sense of vitality she had when she was discharged. Furthermore, she felt that the impact of the traumatic event changed her outlook on life:

Daphne: "Ek het die hele nag deur en die helfte van die volgende dag net op 'n hopie op die bank gesit en tjank... daai ondervinding het van my 'n bang mens gemaak."

Daphne: "I just sat on the couch in a heap and cried for the whole night and half of the following day... that experience turned me into a scared person."

Other participants faced relentless ongoing stress e.g. returning to abusive or manipulating home environments. They reported feeling caught up in family conflicts and that they often played the role of mediator. Feeling overwhelmed by the

continuous nature of their stressors, which didn't improve after discharge was experienced as a major setback in their recovery process:

Sarie: "In die huis is al die lelike dinge gedoen, hy rand my party dae aan as hy so gedrink is. Hy wou my al uit 'n kar uit skop wat ry.... Ek is 'n totale wrak by daai huis."

Sarie: "All the nasty things happened at home, some days he assaults me when he has had too much to drink. He wanted to kick me out of a moving car... I am a total wreck at home."

Elna: "Ek het baie met my seun gesukkel... Want ek moes baie vir hom cover en uhm sodat my man die dinge nie moet uitvind nie. Dit het dinge vir my baie moeilik gemaak by die huis."

Elna: "I had a lot of issues with my son... I had to cover for him a lot and uhm so that my husband didn't find out. It made things very difficult for me at home."

Marie: "Vir my voel dit asof ek die hele tyd die vrede moet bewaar... Dis asof daar die hele tyd so 'n worsteling is tussen hom en my en die kinders..."

Marie: "It feels as though I have to continually keep the peace... It is as though there is a constant battle between him and me and children..."

Some participants struggled to cope with life after discharge, because they felt overwhelmed by stressors that they had to face. These stressors varied from not being able to cope with daily responsibilities to traumatic events that they were exposed to.

4.3.2.3.3 Being faced with lingering and re-occurring symptoms of depression

The presence of depressive symptoms, which either lingered from the point of discharge or re-emerged after discharge, was another factor, which made it difficult for participants to deal with stressors.

Participant accounts highlighted the immense challenge of trying to deal with stressors while battling the debilitating effect of depressive symptoms. As seen in the quotes below, they felt depleted of energy and incapable of facing challenges:

Elna: “Dit was maar net dat ek nie heeltemal oor die depressie was nie. Ek het maar gesukkel om aan die gang te gaan, om oor daai depressie te kom.”

Elna: “It was just that I wasn’t completely over the depression. I struggled to get going, to get over the depression.”

Sarie: “...toe ek hier uitstap toe dog ek nou’s ek reg vir die res van my lewe, en ek het nie geweet dit gaan terugkom nie.”

Sarie: “... when I walked out of here I thought that I was going to be okay for the rest of my life, I didn’t know that it would come back.”

Elsabe: ...”binne-in my was geen dryfkrag nie, binne-in my was geen lus om niks te doen nie.”

Elsabe: “...inside me was no motivation; inside me was no desire to do anything.”

Andrea: “I just got really lethargic... I kind of lost the nerve to do things that I should be doing.”

Neels: “Ek het niks gevoel oor niks.”

Neels: “I just didn’t care about anything.”

The presence of depressive symptoms was experienced to be debilitating to such an extent that participants felt unable to deal with stressors, which in turn left them vulnerable to relapse.

In conclusion, participants struggled to implement coping skills in order to deal with challenges after discharge. They realised that applying newly learnt coping skills might be more difficult than they anticipated. In addition to that, they felt overwhelmed by stressors to such a degree that they could not deal with it effectively. Lastly, the presence of depressive symptoms left participants with no energy or drive to face problems. These difficulties resulted in feelings of disappointment as life after discharge was more challenging than they anticipated it to be.

4.3.2.4 Conclusion of theme two

Participants were discouraged to find that life after discharge was not what they anticipated it to be. They found it challenging to step back into their “old” lives as they realised that they still faced many of the same problems. Participant accounts also highlighted the fact that the hospital environment was experienced as more conducive for recovery than the environments at home to which participants returned to. They experienced a marked difference between life in hospital and life outside of hospital. Furthermore, participants struggled to implement the coping skills that they have learnt in hospital as they continued to battle with depressive symptoms. All of these factors were experienced as challenges, which contributed to their re-admission.

The second theme is illustrated in the following diagram:

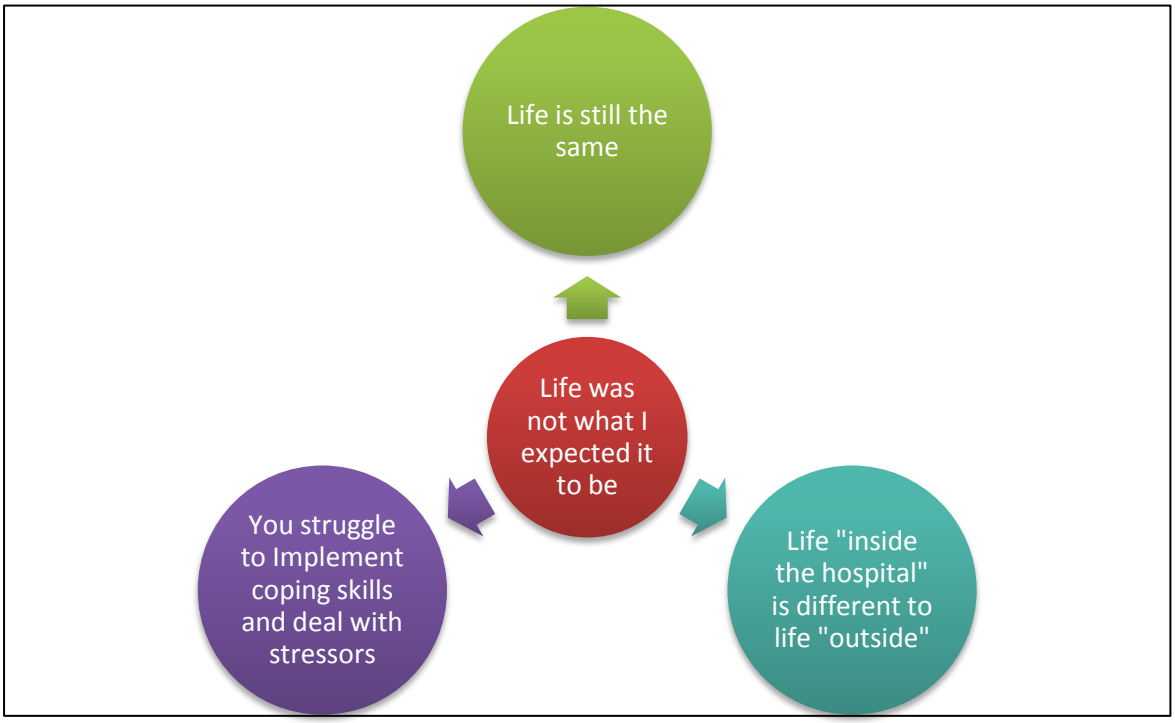


Figure 4.2 Factors contributing to the realisation that life was not what it was expected to be.

4.3.3 Theme 3: I did not feel supported after discharge

In this theme, participants reflected on the quality and quantity of support that they received after discharge. All the participants had some form of support being offered to them by family, friends or work colleagues. However, the degree to which these attempts were experienced as being helpful varied. Only one participant, Andrea, felt adequately supported after discharge. Five participants felt supported in some way, although it was not experienced as being sufficient. Five participants did not feel supported at all.

One of the challenges that participants encountered after discharge was that their illness was used against them. They reflected on various obstacles in the process of receiving support. Furthermore, participants acknowledged that their loved ones did not always know how to support them and came to the realisation that family members might need intervention as well. The meaning units, clusters and sub-themes contributing to theme three are listed in Table 4.3 below:

Table 4.3 Sub-themes, clusters and meaning units of theme three

Theme 3: **I did not feel supported after discharge.**		
Sub-themes:	**Clusters:**	**Meaning units:**
My illness was used against me.	It is difficult to face the stigma.	A psychiatric hospital is associated with madness. Your start doubting your own sanity. You dread people's reaction when they hear about your admission. It is difficult to admit that you have depression.
	I became the problem in their eyes.	All eyes are on you. Being blamed for everything that goes wrong.
There are stumbling blocks in seeking and providing support.	It is difficult to receive support if you do not open up.	Hiding your true feelings. You do not want to burden your spouse. Keeping people at arm's length. Unrelenting questions infringe on your privacy. Unrelenting questions remind you of the past.
	Poor insight makes it difficult for relatives to provide support.	Relatives don't what depression really is. They want to help but don't know how. Relatives need support too.

4.3.3.1 My illness was used against me

Participants did not feel supported after discharge as they felt that their illness was used against them. Firstly, they were confronted with the stigma associated with MDD as they experienced that disclosure of their diagnosis and hospitalisation was sometimes met with disapproval. Secondly, participants felt blamed for everything that went wrong in relationships as problems were attributed to the fact that they were diagnosed with a psychiatric disorder and therefore this implied them to be mentally unstable. Their accounts portrayed a sense of hurt, as they felt burdened by blame.

4.3.3.1.1 It is difficult to face the stigma

Participant accounts portrayed a sense of separation. Separation between "us" and "them" between those who had first-hand experience and therefore understood psychiatric hospitalisation and those only familiar with everyday life. Participants described how people in their lives reacted with disapproval as they became aware of their admission. A psychiatric hospital was associated with mental illness, which in turn was associated with madness. Participants experienced this association as hurtful.

Sarie: "Toe kom ek agter nee, my man dink 'n plek soos hierdie is vir mal mense."

Sarie: "Then I realised that my husband thought that a place like this is for mad people."

Rene: "Almal sê 'o die malhuis' hoe kan iemand wat so normaal voorkom... hoe kan sy in die malhuis land, dit was almal se reaksie."

Rene: "Everyone said 'o the madhouse' how can someone that looks so normal... how can she end up in the madhouse that was everyone's reaction."

Stefan: "... almal dink jy't nou jou kop verloor..."

Stefan: "... everyone thinks that you have now lost your mind..."

Andrea: "Nowadays they think places like these are the Looney Bin."

The quotes above and Andrea's quote below highlighted an interesting phenomenon. Three of the participants described the feeling of stigmatisation that they perceived, but without experiencing any direct disapproval by others due to their diagnoses. They used words like "they" and "everyone" indicating a general perception of what others might have thought of their admission.

In fact, Andrea's experience has been supportive as opposed to stigmatising as is seen in the following quote:

Andrea: "People were friendly because they felt, the hospital's got such a good name, one of my husband's work mates has been here before. So it was good."

However, whether it was due to perceived stigma or to the actual lived experience of stigma, the negative associations or responses of others were experienced as hurtful. Participants explained that they came to the conclusion that there must be something "wrong" with them. As seen in the quotes below, they experienced shame, which was internalised and resulted in self-doubt:

Stefan: "...so daar's fout met jou."

Stefan: "...so there must be something wrong with you."

Rene: "Ja, dit laat mens nogal sleg voel… dit sit verder stres op jou want jy dink ja tot hulle dink jy het dit nou heeltemal verloor."

Rene: "Yes, it makes you feel rather bad... it places further stress on you because you think yes even they think that you have totally lost it."

Furthermore, the experience of stigma resulted in a wariness to share information about their illness, which in turn greatly reduced opportunities to receive support. It is impossible to be supported if those around you are not aware of your difficulties. However, the dread of stigmatisation was so intense that participants chose not to engage with others. The pure thought of having to face other people stirred up feelings of anxiety, as is seen in the quotes below:

Elsabe: "Dis 'n klein dorpie... almal weet nou klaar ek is hierso. So ek is bang om terug te gaan..."

Elsabe: “It is a small town... everyone already knows that I am here. So I am scared to go back...”

Rene: “Veral die mense wat half die konnektasie maak en vra waar was jy... wat om vir hulle te sê. Dis moeilik om hulle te dodge.”

Rene: “Especially the people who sort of make the connection and ask where you were... what to answer them. It is difficult to dodge them.”

The fear of stigmatisation partly withheld participants from seeking support. They did not have answers at hand to explain their absence from work or activities in town and preferred to avoid contact altogether.

Stefan summarised the essence of participants’ experiences relating to stigma with the following quote:

Stefan: “...dis moeilik om te erken jy het depressie.”

Stefan: “it is difficult to admit that you have depression.”

4.3.3.1.2 I became the problem in their eyes

Participants described the shifting of blame that occurred in their relationships, as they experienced that their illness was used against them in conflict situations. They felt that their emotional difficulties were cited as the cause of all relational problems. They felt unfairly blamed, had to bear the brunt and take full responsibility for what was essentially a shared problem. Participants felt blamed and not supported at all. As the following quotes illustrate, the focus was shifted from the problematic situation to them as person:

Stefan: “Die fokus is heeltemal op jou en nie meer op die probleem nie.”

Stefan: “The focus is entirely on you and not on the problem anymore.”

Sarie: “... elke argument wat opgekom het, elke dingetjie wat verkeerd gegaan het, dan hy’t gesê ‘sy’s mos mal die ding, sy kom uit ’n psigiatriese hospitaal uit’...”

Sarie: “... every argument that came up, every little thing that went wrong, he said ‘she is crazy, she comes out of a psychiatric clinic’...”

This sub-theme highlighted the effect of other people's responses on participants' experience of stigma. Having their illness used against them after discharge did not foster an environment of support and was another challenge that participants had to face after discharge.

4.3.3.2 There are obstacles in seeking and providing support

Despite experiencing some negative responses regarding their illness as described in 4.3.1.3.1(My illness was used against me), participants reported that there were sincere attempts to support them. However, the success of attempts to seek support by participants as well as attempts to provide support by their loved ones was questionable. It became clear that support was a shared endeavour and that obstacles could occur in the process of giving as well as receiving support.

4.3.3.2.1 It is difficult to receive support if you do not open up

Participant accounts portrayed a sense of wariness to disclose their true feelings. Opening up was associated with increased vulnerability, which was experienced as daunting. It was easier to hide behind a facade of positive emotions and to convey the message that they were seemingly coping well after discharge. Furthermore, disclosing troubling feelings was experienced as a weakness, which was not what participants wanted to depict to the world after discharge. Withholding difficulties from loved ones also served a protective purpose as participants did not want to burden them with their hurt. Attempts to camouflage their true feelings were portrayed by the quotes below:

Elsabe: "...ek het maklik weer die gesig opgesit van jy weet 'Ek's okay, moenie worry nie, ek's okay, ek is sterk."

Elsabe: "...I just put on the face of 'I am okay, do not worry, I am okay, I am strong."

Oscar: "...jou gevoelens steek jy weg..."

Oscar: "...you hide your feelings..."

Neels: "'n Uitdaging wat daar gewees het was miskien om te probeer tough wees, om nie vir my vrou te wys hoe ek voel nie."

Neels: “A challenge that there was was maybe to try and be tough, not to show my wife how I felt.”

Stefan: “Eintlik, ek laat nie mense naby my toe nie. So hulle sit half aan daai kant van die baksteenmuur. Hulle kon nie naby kom nie.”

Sefan: “Actually, I do not allow people close to me. So they really sit on the other side of the brick wall. They could not come close.”

Participants reflected on the reasons for their reluctance to disclose their feelings that in turn withheld them from seeking support. Some participants felt pressured to disclose their feelings and experiences of hospitalisation by being faced with unrelenting questions. Although these questions might have been asked out of real concern, participants did not experience it as being helpful. Instead of enabling conversation, the ceaseless nature of questioning resulted in the emotional withdrawal of participants. Questions were experienced as burdensome, which is evident in the following quotes:

Elsabe: “Wat my absoluut mal gemaak het is die mense wat vir my vra ‘Hoe gaan dit?’...”

Elsabe: “What really drove me nuts were the people who asked ‘How are you?’...”

Elna: “Wat het hier gebeur? Hoe was dit gewees. Daai tipe van goeters. En hoe meer ek vir hulle probeer verduidelik uhm dit is my besigheid, dit is my dinge en niks met hulle uit te waai nie, hoe meer het hulle aangehou en aangehou en aangehou.”

Elna: “What happened here? How was it. Those kinds of things. The more I try to explain to them that uhm it is my business, it is my issue and does not have anything to do with them, the more they just kept on and on and on.”

Stefan: “ Almal wil weet wat aangaan... dis oor en oor en oor, dit hou nie op nie... dit was verskriklik...”

Stefan: “Everyone wants to know what is going on... it happens over and over and over again, it never stops... it was horrible...”

Two participants described how they dealt with deflecting the pressure that being faced with unrelenting questions brought about.

As Stefan felt pressured to answer but did not want to share intimate information, he resorted to telling untruths. The following quote illustrated his desperation to divert other people's attention away from himself:

Stefan: "Ek het naderhand maar net goed uitgedink om net te sê dat dit net moet stop, sodat niemand my meer moet vra nie."

Stefan: "I eventually invented stuff to say just so that it would stop, so that no-one would ask me anymore."

Elna resentfully caved in to the pressure and felt exposed as she shared more information than she was comfortable with. When asked how she felt after divulging information, she answered the following:

Elna: "Mislukking. Asof ek nie my eie sake vir myself het nie... ek hou nie daarvan nie..."

Elna: "Failure. As if I don't keep my private matters to myself... I do not like it..."

Having to face unrelenting questions hampered Stefan's recovery as answering well-meant questions implied reliving the painful past:

Stefan: "... jy herleef dit elke liewe dag. Daar's altyd iemand nuut's wat vir jou vra wat hoe gaan dit, wat het gebeur... Jy's die heeltyd bewus daarvan..."

Stefan: ".. you relive it every single day. There is always someone new who asks you how you are doing, what happened... You are aware of it the whole time..."

In addition to unrelenting questions that were experienced as a stumbling block in seeking support, Rene and Oscar reported that family dynamics prevented them from opening up.

Rene hesitantly described her husband as a source of support after discharge. Although he formed a cornerstone of her support structure, frequent conflicts in their marriage had a disconfirming effect on the support he was able to provide:

Rene: "Hy's deel van die… van die… emosionele ondersteuning maar hy is ook deel van die probleem."

Rene: "He is part of the... of the... emotional support but he is also part of the problem."

Similarly, Oscar was ambivalent about his wife's supportive role in his recovery from MDD. His account highlighted the pressures of family life in which his need for support had to compete against the children's need for care:

Oscar: "... in die aand as sy by die huis kom dan moet die kinders gebad word, die kinders moet uitgesorteer word, kos moet gemaak word, al daai tipe van dinge. So sy het nie tyd gehad om enigsins om te sien na my ook nie."

Oscar: "... in in the evening when she gets home the children have to be bathed, the children have to get sorted, food has to be prepared, al those kinds of things. So she did not have the time to take care of me too."

Participants acknowledged that they were not entirely honest about their mood state. They reported that having to face unrelenting questions was experienced as pressure to open up. Not allowing other people close enough to offer support contributed to their experience of not being sufficiently supported after discharge.

4.3.3.2.2 Poor insight makes it difficult for relatives to support you

In addition to stumbling blocks in receiving support, participants also described a major stumbling block that affected the quality of support that was offered to them. As seen in 4.3.1.1.2 (External pressures leading to discharge) family's poor insight was one of the underlying causes, that resulted in participants feeling pressurised to be discharged before they were ready. However, participant accounts highlighted the profound effect of poor insight on the amount and quality of support offered to them after discharge as well.

It emerged that families did not necessarily understand how debilitating depression was. Encouraging words and acts of support that might have sufficed in other situations, proved not to be effective. Depression was merely viewed as a changing mood state and not as an illness. This view resulted in limited empathy and a “pull up your socks” approach. Some relatives were empathetic but had difficulty expressing their support in a helpful way, while the sympathy of others was expressed in the form of pity, which was experienced as being patronising and not meaningful at all.

Although the shared experience of participants captured a sense of frustration with their relatives’ lack of understanding and support, the outcome of poor insight was illustrated in various ways:

Liezel: “Want nou verstaan hulle nie. Jy is ‘down the dumps, so what”. Werk daaraan, more voel jy beter.”

Liezel: “Because they don’t understand. You are down in the dumps, so what. Work on it, you will feel better tomorrow.”

Elsabe: “...dat hulle nie regtig weet wat is die regte woorde of die dade om te gebruik om hierdie persoon te ondersteun nie.”

Elsabe: “...that they don’t really know what the right words or deeds are to use in order to support this person.”

Stefan: “Hulle het die persepsie... jy’s hierdie arme ou dingetjie en wat ookal. Ek dink nie hulle verstaan nie.”

Stefan: “They have this perception... you are this poor little thing and whatever. I don’t think they understand.”

Most participants concluded that their relatives would benefit from an opportunity to improve their insight. They felt that their relatives lacked understanding of the symptoms of depression and how they influenced their behaviour. They also identified learning needs relating to the recognition of relapse as well as effective strategies in providing support. As seen in the quotes below, participants highlighted the importance of a systemic approach, where the focus of treatment should not only be on MHCUs but also on the significant people in their support networks:

Liezel: “Hulle moenie net aan jou werk nie, hulle moet aan die mense by die huis saam werk. Dat mense by die huis kan verstaan hoekom is jy so.”

Liezel: “They shouldn’t just work on you, they should also involve the people at home. That people at home can understand why you are like this.”

Elsabe: “...dis baie belangrik dat julle die familie na waantoe jy gaan, dat daardie familie ‘n sessie het en dat hulle toegerus is met wat is depressie en wat is seer, wat is swaar en hoe hanteer ek dit.”

Elsabe: “... it is very important that the family that you return to, have a session so that they are equipped with what depression is and what hurt is, what is difficult and how do I manage it.”

Participants attached so much value to improving their relatives’ insight, that they even suggested that relatives attended some of the occupational therapy groupwork sessions:

Daphne: “... dit sou nogal nice gewees het as iemand nou getroud is, dat die eggenote dit ook bywoon. En ook voorbereid is om die nodige hulpverlening te verskaf en die gevaartekens van relapse raak te sien.”

Daphne: “... it would have been nice if someone is married, that the spouse can also attend. And therefore also be prepared to help and to recognise the warning signs of relapse.”

As participants became aware of their relatives’ lack of insight and the influence it had on their experience of support, they also developed an understanding of the type of information that relatives should be provided with.

4.3.3.3 Conclusion to theme three

Participants realized that the level of support of that they received after discharge, had an influence on their recovery process. The experiencing of stigma and being burdened by blame, led to the conclusion that their diagnosis was used against them. Furthermore, they became aware of various stumbling blocks that hampered the receiving as well as the giving of support. The majority of participants did not feel

adequately supported after discharge, which was one of the challenges that contributed to their re-admission.

Theme three is illustrated in the following diagram:

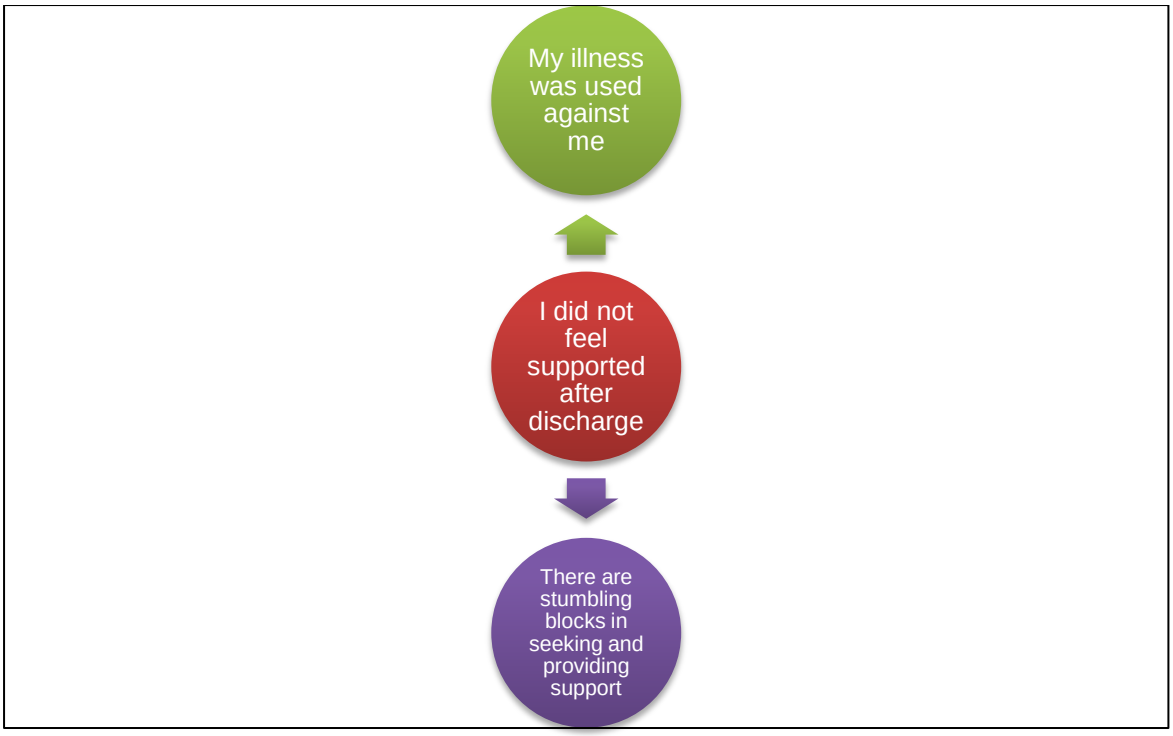


Figure 4.3 Factors contributing to the experience of not feeling supported after discharge.

4.4 Findings relating to the second research question

This research question aims to provide insight into the value that participants would attach to a support group after discharge as an extension of the in-patient occupational therapy programme. It included the supportive factors that they associated with attendance and highlighted the role that the hospital has to play in terms of ongoing support after discharge.

4.4.1 Theme 4: Support groups could be valuable

In this theme, participants' perception of the value of support groups was discussed as the first sub-theme. The majority of participants felt that they would benefit from attending a support group after discharge, as it would help them cope with life. However, reasons for possible non-attendance also emerged.

The hospital was cited as the preferred venue for a support group in the second sub-theme thus acknowledging that the hospital had a role to play in terms of ongoing support after discharge. The meaning units, clusters and sub-themes contributing to theme four are listed in Table 4.4 below:

Table 4.4 Sub-themes, clusters and meaning units of theme four

Theme 4: **Support groups could be valuable.**		
Sub-themes:	**Clusters:**	**Meaning units:**
A support group would help me cope with life.	Smoothing the transition.	A support group will help you to settle back into life after discharge. It would be helpful to reflect on your progress after discharge. Reconnecting with staff will be encouraging.
	Support to apply what you have learnt.	It would remind you of what you have learnt in hospital. It would equip you to deal with stressors.
	The value of shared experiences.	You can encourage others with what you've learnt. People who have been through a similar situation really understood how you feel. It will be encouraging to see how other people cope with their difficulties.
Support groups could do more harm than good.	My story is mine and their stories are theirs.	I will not open up to strangers. My own issues are challenging enough.
I prefer a familiar environment.	I would like to attend a support group at the hospital.	It will be easier to return to a familiar place. It will be easier to open up to familiar people. I live too far away.

4.4.1.1 A support group would help me cope with life

The majority of participants said that they would value attending a support group after discharge. The prospect of a support group was generally met with a sense of eagerness and it became clear that participants held great expectations regarding the positive effect of such a group:

Neels: "... dit gaan wondere doen aan 'n mens, wonderlik wees, dit sal."

Neels: "... it will work wonders, it will be great."

Elsabe: "Ek dink verseker dat dit baie waarde sal bydra."

Elsabe: "I am convinced that it would be valuable."

Daphne: "Absoluut. Ek het dit trouens vir een van die ander arbeidsterapeute voorgestel."

Daphne: "Absolutely. As a matter of fact, I suggested it to one of the other occupational therapists."

They reflected on several factors, which would motivate them to attend. These included facilitating a smooth transition process from hospital to home, helping participants to deal with stressors and providing an opportunity to benefit from shared experiences. Participant accounts indicated that many of the difficulties relating to coping with life after discharge as expressed in the first three themes could be addressed by support group attendance.

4.4.1.1.1 Smoothing the transition

Participants anticipated that a support group would help them through the transition between hospital and home. As described in theme two, life after discharge was not what participant anticipated it to be and they felt overwhelmed by the realities that awaited them. The stark contrast between the experience of protection in hospital and the feeling of vulnerability after discharge was described. A support group could facilitate the adjustment to life after discharge by providing an opportunity to reflect on difficulties that participants experienced in the transition process. As seen in the quotes below, participants acknowledged their need of support after discharge:

Andrea: "You're out there in the world. In a support group you get help in making that re-adjustment pattern to the outside world."

Elsabe: "...jy kan nie hier uitstap... en dan is ek reg vir die wêreld daarbuite nie, want dan begin die ondersteuning eers."

Elsabe: "...you can't walk out of here... and then I am ready for the world out there, because that is when the support really starts."

Two participants expressed a specific desire to reconnect with the occupational therapists and other MHCUs. Their accounts depicted a longing to return to the place associated with nurturing and protection, even if it was just for the duration of one group session:

Stefan: "... mens moet eerder eenkeer weer miskien terugkom hiernatoe en opvolg oor wat gebeur."

Stefan: "... one rather has to come back here once to follow up on what has happened."

Daphne: "... om net weer 'n bietjie kontak te he met van die mense en die die arbeidsterapeute sal vir my van onskatbare waarde wees."

Daphne: "... just to have a little contact once again with some of the people and the occupational therapists would be of immense value to me."

Similarly, Oscar also expressed the need to return to the hospital to attend a support group. However, he also valued the prospect of being physically and emotionally removed from his problems at home. For him, a support group would provide respite:

Oscar: "Jy kom in die eerste plek kom jy weg van die huis af wat klaar 'n pluspunt is, jy kom weg uit jou omstandighede van die huis af."

Oscar: "You get away from home which is already a plus, you get away from your situation at home."

In conclusion, support groups were regarded as a valuable resource to bridge the daunting gap between hospital and home.

4.4.1.1.2 Support to apply what you have learnt

In theme two, participants described an inability to apply the coping skills that they had learnt in hospital, partly due to poor recollection of information shared in hospital. They felt overwhelmed by stressors that left them unable to manage their daily lives. Most importantly, participants acknowledged that recovery from depression was an ongoing journey in which challenges would continually have to be faced. Therefore, support groups were perceived as an ongoing source of help and inspiration. Participants recognised the empowering aspect of support group

attendance as it could refresh the information on coping skills and provide encouragement to deal with everyday stressors.

Participants reported a longing for continued support after discharge. As Neels had trouble with recalling all the coping strategies that he learnt during hospitalisation, he valued the information-sharing aspect of support group attendance. He expressed the need to be reminded of strategies and to be encouraged to implement it:

Neels: "Dit sal dat jy nie die drade verloor nie...dit sal die mense net verder encourage en 'o ja ek dit dit geleer'..."

Neels: "That you won't lose the important concepts... it will just encourage the people again and 'oh I have learnt this'..."

As seen in the quote below, Daphne acknowledged the substantial amount of work still required in her process of recovery would therefore value follow-up sessions with the occupational therapists:

Daphne: "...niemand gaan oornag reg kom nie, nie vir een van ons nie. Ons almal sal almal by die huis moet werk aan die onderliggende probleme..."

Daphne: "...no-one will recover overnight, not one of us. All of us will have to continue working on the underlying issues at home..."

Elna elaborated on the encouraging aspect of support group attendance, by highlighting the value of resilience that support group attendance could foster. Mental Health Care Users would be able to "bounce back" and recover faster after setbacks if they had the appropriate support:

Elna: "... dit sal die pasiënte baie help om meer aktief of meer dinge te doen, vinniger oor die stres te kom as hulle ondersteuning het. "

Elna: "...it will help the patients to become more active or to do more things, to get over the stress quicker if they have support."

In conclusion, participants were of the opinion that support groups could provide relief in dealing with the chronic nature of depression and the accompanying challenges.

4.4.1.1.3 The value of shared experiences

Support groups were perceived as a place of connectedness and understanding, which was in contrast to the post-discharge experiences of isolation and stigma that participants described. A support group was regarded as a safe environment in which the sharing of experiences was facilitated. Although participants valued the input from staff during hospitalisation, they strongly felt that only someone who has been through a similar situation could truly understand the depth of their pain and desperation. Therefore, the encouragement that they would receive from someone who has been through a similar situation was anticipated to be especially meaningful:

Sarie: "Net om te sien wat die mense om uit daai situasie uit te kom waar jy wil selfmoord pleeg. Weet jy ek is twenty-four seven besig om selfmoord te beplan en as daar ander sulke mense is wat kon regkom, wat genees is dan sal ek graag dit... wil bywoon."

Sarie: "Just to see what people do to get out of the situation where you want to commit suicide. I am busy planning suicide twenty-four seven and if there are other people who have improved, who have recovered then I would like to attend it."

Elsabe: "Jy het 'n groep nodig wat in dieselfde situasie as jy was, jy weet... en al kom jy na my toe en sê 'Elsabe, ek weet hoe jy voel, ek kan myself nie indink hoe jou week moes wees nie', gaan jy nie kan soos 'n vrou wat self haar kind verloor het voel nie..."

Elsabe: "You need a group that has been in the same situation as you have been, you know... and even if you come to me and say 'Elsabe, I know how you feel, I can't imagine what your week must have been like', you won't be able to feel it like a woman who has lost a child herself..."

Furthermore, the sharing of experiences could enable the development of altruism. A support group could enable participants to take up the role as encourager as they have had first-hand experience of a similar situation. Neels expressed the desire to use what he has learnt from his painful experiences to the benefit of others in the group:

Neels: “Om ‘n ander ou te probeer help want ek weet hoe was die situasie en ek gun dit vir niemand nie.”

Neels: “To try and help someone else because I know what it was like and I wish it upon no-one.”

In conclusion, being able to learn from other MHCUs who are in the same boat would help participants to cope with the challenges after discharge more effectively.

4.4.1.2 Support groups could do more harm than good

While nine of the eleven participants felt that attending a support group would be valuable, two participants reported that they would not consider attending such a group. In the context of this study, it is necessary to acknowledge possible factors which participants perceived would make attending a support group non-beneficial as well as those which would encourage non-attendance.

4.4.1.2.1 My story is mine and their stories are theirs

The two participants, who did not anticipate a support group to be helpful, expressed the need for clear boundaries between their narratives and those of other MHCUs. The following reasons emerged as motivation not to attend a group: the confidentiality of one’s own life story and not wanting to be burdened by other people’s difficulties.

Liezel’s reluctance portrayed the value that she attached to confidentiality and privacy. Sharing her personal problems with a group of people was associated with vulnerability that seemed too daunting to risk:

Liezel: “So dit maak dit vir jou moeilik want hier sit 'n hele groep mense, en elkeen vertel sy storietjie maar dis steeds 'n seer teer punt om voor vreemde mense jou storie te vertel. Dit sal ek byvoorbeeld glad nie doen nie.”

Liezel: “So it makes it difficult because you sit in a group of people, and everyone tells his own little story but telling your story in front of strangers is still a delicate issue. I would definitely not do something like that.”

Marie’s account on the other hand portrays a sense of depletion. She described how she lacked the emotional capacity to listen to other people’s problems in a group

setting. Having to deal with her own stressors was already experienced as too much to bear. Participation in a support group was therefore anticipated to be burdensome:

Marie: "Ek dink mens sukkel om met jou eie issues klaar te kom so persoonlik sal ek nie so groep wil bywoon nie."

Marie: "I think one already struggles with your own issues so I personally will not attend such a group."

In conclusion, not all participants viewed support group attendance as the antidote to the challenges associated with depression post-discharge.

4.4.1.3 I prefer a familiar environment

In this sub-theme, participants expressed their preferences regarding the support group setting. Their choice seemed to be influenced by the distance from home as well as familiarity of the environment.

4.4.1.3.1 I would like to attend a support group at the hospital

Participants who lived within a reasonable travelling distance from the hospital unanimously preferred the hospital as setting. They valued the familiarity of the hospital environment, staff as well as other MHCUs. This sense of acquaintance created a feeling of safety, which was anticipated to facilitate attendance and participation:

Rene: "Ek dink net dis moeiliker om jouself te kry op 'n plek om by 'n nuwe een aan te sluit … al ken jy net die gesig, dis makliker, vir enige mens is dit makliker om na iemand toe terug te gaan… al was mens net by een van hierdie arbeidsterapeute en een van julle klasse... dan dink ek 'n mens sal makliker teruggaan."

Rene: "I just think that it is harder to convince yourself to join a new group... it is easier for anybody to go back to someone, even if you just know their face... even if you have just been to one of the occupational therapists and one of your classes... then I think it would be easier to go back."

Stefan: "Ek dink dis die beste want... jy kry 'n gemaklikheid hier."

Stefan: “I think it would be the best because... you feel comfortable here.”

Oscar: “Jy ontmoet mense wat jy alreeds ken met wie jy gemaklik is om oor goed te gesels, en bereid is om jou hart uit te praat.”

Oscar: “You meet people whom you already know with whom you are comfortable to talk to, willing to share your heart.”

The only reason cited for attending a group in a setting other than the hospital, related to the practical issue of travelling distance. Participants, who lived in towns or cities other than Pretoria, suggested that a group be held as close to their home as possible:

Andrea: “It will have to be in my home town.”

Stefan: “Wel in die dieselfde stad. So naby as moontlik aan die huis...”

Stefan: “Well in the same city. As close as possible to home...”

In this sub-theme, the hospital emerged as the preferred venue for a support group as value was attached to the reassuring nature of the hospital environment.

4.4.1.4 Conclusion to Theme four

The majority of participants reported that they would value the attendance of a support group after discharge. The meaning that they attached to a group revolved around the support that it would provide to them in order to cope with life after discharge. Participants anticipated such a group to provide support with the transition between hospital and home, to equip them to cope with stressors as well as to create an opportunity to share experiences.

Participants also reflected on the role that the hospital has to play in terms of ongoing support, as they indicated that the hospital would be their preferred setting to host a support group.

Theme four is illustrated in the following diagram:

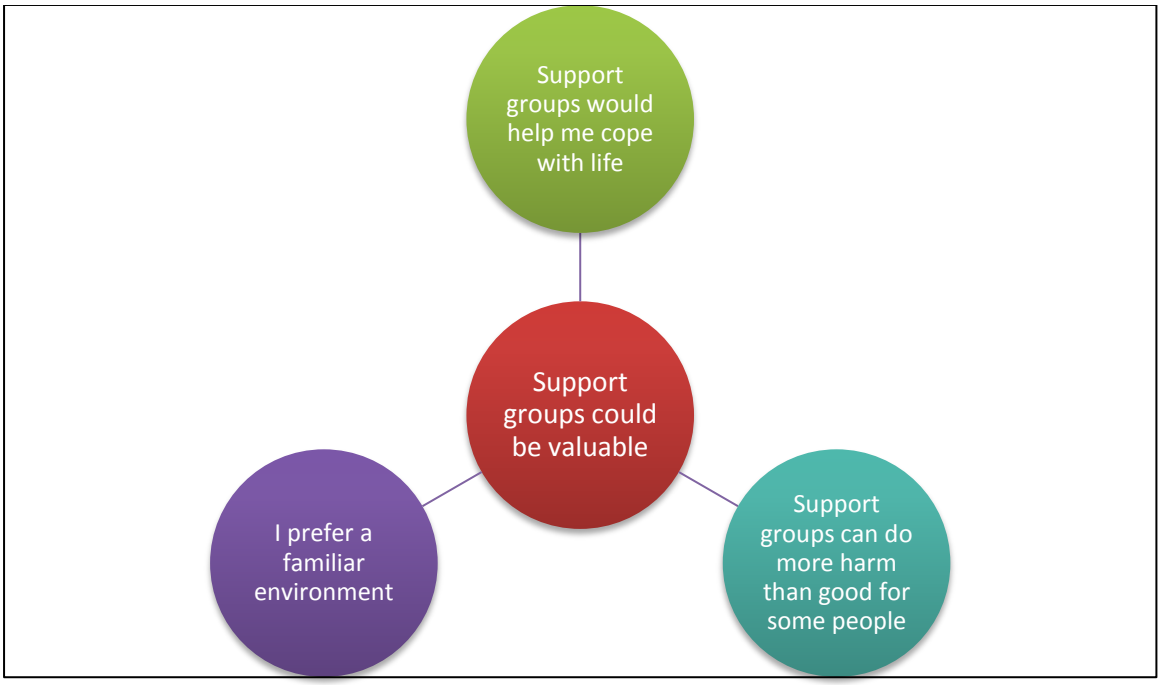


Figure 4.4 Diagram illustrating perceptions regarding support group attendance after discharge.

4.5 Main findings of the study

Participants described several challenges that they had encountered during hospitalisation and after discharge that they perceived to have contributed to their relapse and readmission. Firstly, participants described the factors that prevented them from fully benefitting from hospitalisation. Secondly, participants reported that they were taken aback by the stark contrast between life in hospital and life "outside" and described the difficulties that they had experienced when adjusting to life after discharge. Thirdly, participants reflected on the factors that made them feel unsupported after discharge. Lastly, participants felt that attending a support group after discharge would be valuable, although they acknowledged that it could do more harm than good.

CHAPTER 5
DISCUSSION

5.1 Introduction

The purpose of this study was to explore the challenges that MHCUs diagnosed with MDD experience following a period of hospitalisation that could contribute to re-admission with in a six-month period. Additionally, the purpose was to explore their perception of the potential value of support groups after discharge. In this chapter, findings of the study presented in Chapter 4, are interpreted, discussed and critically reviewed in relation to literature. It concludes by reflecting on the importance of this information for service delivery in occupational therapy.

5.2 Challenges faced by MHCUs that contributed to readmission

Although various clinical variables have been identified relating to the recurrence of MDD (36)(54), the findings presented in Chapter 4 suggest additional challenges that were experienced by participants in the post-discharge period which contributed to their relapse and readmission. These challenges will be discussed, followed by a discussion on the perceived value of support groups after discharge.

5.2.1 Inability to fully benefit from hospitalisation

In Theme 1 of this study, participants described their inability to fully benefit from hospitalisation. One possible explanation for their inability to make the most of their time in hospital, was that their ability to learn was compromised. Participants struggled to concentrate, a typical symptom of MDD (43), and sufficiently absorb the information presented on coping skills during occupational therapist-led thematic group sessions so that they could remember the information and skills taught in order to apply it upon discharge. Furthermore, participants reported that they felt too emotionally overwhelmed by the experience of a first psychiatric hospitalisation that they could not focus their attention on their recovery. Another relevant factor to this finding is that the implementation of managed healthcare resulted in a short hospital admission which restricted the time available for learning to take place.

5.2.1.1 Cognitive symptoms of depression

As described in Theme 1, participants could not fully benefit from the therapeutic programme during admission, partly due to their inability to concentrate and retain information. In line with current literature which report that MDD impairs learning (49)(50), participants in this study perceived that their depressive symptoms had the most profound influence on the learning process.

One of the occupational therapy treatment goals at the research site was the improvement of coping skills, using thematic groups within a cognitive behavioural frame of reference. However, in order for participants to make the most of these learning opportunities, cognitive domains such as attention and memory need to function optimally. The question of the timing of group work that involves learning during the acute phases of MDD has been raised before in the literature. Occupational therapists in Canada found that MHCUs benefitted from re-attending thematic groups after they have been discharged from an acute psychiatric hospital, suggesting that they struggled with the cognitive content while still acutely unwell (192). The Canadian study concluded that group content should reflect the readiness of MHCUs to absorb information. Affirming these results is a study by Tanaka, Ishikawa, Mochida, Kawano & Kobayashi (193) which concluded that although attendance of educational groups during the acute phase of MDD contributed to the perception of recovery, it did not have an effect on readmission rates, therefore questioning the efficiency of learning that took place.

This is in line with the findings of the current study that showed that participants lacked the necessary cognitive skills during admission in order to make the most of learning opportunities presented to them. Participants perceived that they were unable to sustain their concentration during thematic occupational therapy groups. This impaired their ability to absorb the new information that was presented to them during therapy sessions. This finding was also supported by Tursi, Baes, Camacho, Tofoli & Juruena (194) who reported that although educational groups improves psychosocial functioning in MDD, compromised executive functions prevented participants from optimally benefitting from group sessions and therefore influenced MHCUs' ability to cope with challenges after discharge.

It is important to note that the influence of impaired cognitive skills on the learning experience not only played a role during participation in thematic occupational therapy groups, but extended to the time after discharge as well as cognitive dysfunction continues long after the acute phase of the illness (46). These persistent cognitive abnormalities may therefore affect recall and carry-over of information from the hospital to the MHCUs' "real-life" occupational environments. In this current study, participants described being taught coping skills but that the application of these skills in "real-life" situations was difficult. Thus, strategies to change personal problems could only be applied to a limited extent. Furthermore, poor problem-solving skills contributed to participants' inability to manage stressful situations after discharge, as they were unable to generate possible solutions for problems that they faced.

It can be concluded that during the acute phase of an episode of MDD, which usually is when someone is admitted to hospital, is not the ideal period for critical learning to take place. Mental Health Care Users are too acutely ill to benefit optimally from learning opportunities, especially when the skills that are taught are crucial in improving resilience after discharge.

5.2.1.2 The emotional experience of psychiatric hospitalisation

Participants' first admission to the Private Psychiatric Hospital was described as a difficult emotional experience, which hampered their ability to absorb information and fully benefit from their hospitalisation. The reasons for this could be three-fold: a distressed emotional state due to depressive symptomatology, an awareness of internal pressure to be discharged due to feelings of guilt and the awareness of external pressure by family members to be discharged.

Firstly, participants were faced with their own unsettled emotional state, which could be attributed to depressive symptomatology (43). Literature indicates that MHCUs usually undergo a progressive deterioration in their mental, physical, social and occupational well-being as their condition progresses before seeking professional psychiatric help (55,56). The recommendation of admission to a psychiatric clinic is based on the severity of symptoms and clinical judgement about the clinical risks in each individual case. In general, MHCUs with mild depressive symptoms would not justify hospitalisation and could be treated effectively in a primary care facility; only

MHCUs struggling with severe depressive symptoms that impair their functioning would be admitted. Therefore, individuals who are admitted typically have been through a challenging period leading up to admission and have severe symptoms of MDD, which hamper their ability to absorb information.

Secondly, participants were plagued by feelings of guilt that pressurised them to be discharged before sufficient treatment gains have been made. Participants reported an internal struggle as they felt that they were neglecting their occupational roles and accompanying responsibilities on the one hand, while they acknowledged their own need for treatment on the other.

Thirdly, participants reported that pressure from relatives to be discharged distracted them from focussing on their own treatment needs and in some cases resulted in premature discharge.

In addition to the above-mentioned factors, admission to a psychiatric hospital per se was reported to be a difficult experience. Participants and their family members attached an overwhelmingly negative meaning to their first psychiatric hospitalisation. Similarly to qualitative studies by Stenhouse (126) and Jones (127) which explored the experience of psychiatric hospitalisation, being in an unfamiliar environment with “mad” and seriously ill people where they did not know what to expect, contributed to participants’ feelings of distress. It should be acknowledged that clinical staff might become habituated to the hospital environment and might therefore not be sensitive to the uncertainties of MHCUs regarding psychiatric hospitalisation.

Despite their unsettled emotional state, participants were encouraged to start attending occupational therapy group sessions immediately after admission. This was done partly as a behavioural activation strategy and partly to optimise the relative short length of hospitalisation. This strategy might be unwise in the view of previous research which has shown that memory is impaired when learning takes place under stressful circumstances (195)(196). Therefore, taking into consideration that the ability to learn is compromised when a person is in an unsettled mental state, it is clear that participants could not benefit optimally from their treatment programme, especially during the first few days of admission.

The detrimental influence of a stressful first admission on the learning process is highlighted when contrasting the experience of a first admission to that of second admission. Participants clearly stated that their perception of their second admission to hospital was by far more positive. They perceived that they would benefit more from their time in hospital and would make the most of learning opportunities. In contrast to their first admission, participants had first-hand experience of what admission entailed. They felt that they adapted quickly to a now familiar environment. The effect of negative emotions on learning therefore was diminished during re-admission, as the familiarity of context had a positive influence on participants' emotional state and their ability to absorb new information. They could focus on their recovery and fully benefit from the interventions offered during hospitalisation.

5.2.1.3 The length of stay in hospital

Another relevant factor to participants' inability to fully benefit from hospitalisation is the time available for hospitalisation. It can be argued that the effects of managed healthcare, which directly influenced the length of participants' admission, were not conducive to the optimal utilisation of treatment opportunities.

As the Private Psychiatric Hospital in this study is a private institution MHCUs who are admitted have to have a medical aid scheme or be able to personally carry the cost of hospitalization. When the Medical Schemes Act of 1998 came into being, certain medical conditions received better coverage by medical schemes. Prescribed Minimum Benefits (PMBs) ensured that MHCUs received adequate care for specific pre-determined chronic conditions, so that the MHCU would not be liable for continued medical costs related to the diagnosis and treatment of these disorders. At the time that this study was conducted, Schizophrenia and Bipolar Mood Disorder were the only two psychiatric conditions recognized on the list of PMBs, therefore excluding MHCUs with a diagnosis of MDD. Thus if a client is admitted with a diagnosis of MDD, hospital benefits are limited to a maximum of 21 days per annum or up to 15 out-patient psychotherapy contacts. Should someone require another admission within the same year, the financial burden lies with the MHCU themselves. In the current study, restrictions imposed through managed healthcare

led to some participants being discharged before optimal therapeutic gains have been made.

At the time of this study, the average admission period at the hospital was two weeks and therefore participants were only accommodated during the acute stages of their illness, which is not an optimal period for learning to take place. Participants also reported that it took time to adapt to a new environment and that uncertainty as well as poor self-esteem prevented them from participating in the treatment programme during the first few days of their admission. Furthermore, it can be argued that it is impossible for adequate insight to develop and for sustained behavioural change to occur in such a short period of time. A short hospital stay also implies that MHCUs are discharged at the point of symptom improvement, not remission, which studies have shown to be detrimental to recovery (81)(82).

In conclusion, findings indicate that the acute phase of an episode of MDD is not an optimal time for learning to take place. The cognitive and emotional symptoms associated with MDD, as well as a short length of stay in hospital, impaired the learning process and therefore also the acquisition of coping skills. This experience of compromised learning was one of the challenges perceived by the participants to have contributed to relapse and readmission.

5.2.2 Life was not what I expected it to be after discharge

The second key factor that participants perceived to have contributed to their relapse and readmission relate to the unrealistic expectations that they held regarding their recovery. Although clinicians who use a medical model approach tend to view recovery from psychiatric disorders in terms of symptom reduction (129), the participants in this study viewed improvement of depressive symptoms as only one aspect of their recovery.

Insight into the challenges that participants in this study experienced and perceived to have contributed to their readmission can be drawn from the Recovery model theory. Participants were disappointed when they realised that life was not what they expected it to be after discharge. Two factors were identified in the findings of this study that are contradictory to the principles of the Recovery model theory. Firstly, whereas Recovery model theory acknowledges the reality of mental illness,

participants in this study had unrealistic expectations regarding their mental health. Secondly, their accounts highlighted a restricted sense of responsibility for their own recovery whilst the Recovery model proposes taking control of one's situation.

5.2.2.1 Unrealistic expectations regarding the recovery process

The essence of participants' journey after discharge reflects unrealistic expectations regarding the recovery process which resulted in a deep sense of disappointment when they relapsed. Participants described how they were taken aback when they realised that life was still the same. Although acknowledging that MDD is a recurrent and cyclical disease requiring long-term professional support has been found to be a helpful strategy in managing the disorder (133), participants in this current study expected their recovery to be completed at the time of discharge, after which they did not anticipate any further difficulties. Participants were taken aback when realising how big their remaining support needs were after discharge. As one participant aptly put it: "Your real journey begins after discharge". Findings therefore indicate a need for greater transparency regarding the possible long-term course of MDD.

Being confronted with depressive symptoms once again caught participants off guard and was experienced as a severe disappointment. Resonating with the findings of Desplenter et al. (128), residual or re-occurring symptoms prevented participants from living life in the way that they anticipated after discharge and this was experienced as an obstacle in their journey of recovery. In contrast to participants' high expectations of a depression-free life after discharge, the literature indicate that recovery should be seen as an ongoing process which consists of ebb and flow experiences (132).

It can be hypothesised that unrealistic expectations regarding recovery stemmed from two factors, namely poor insight as well as reluctance to accept the diagnosis of MDD. Firstly, awareness of and insight into one's own needs are necessary in order to identify more appropriate ways of coping. For participants in this study, the development of insight could have been facilitated by attending the thematic occupational therapy groups, resulting in an increased understanding of their life-situations. However, as discussed in 5.2.1.2, the presence of depressive symptoms hampered the learning process and therefore hampered the development of insight.

Validating the results of a study by Nunstedt, Nilsson, Skärsäter & Kylén (122) which explored the way in which MHCUs understand MDD, participants in this current study were only able to reflect usefully upon their illness and develop a deeper understanding of their situations once at home.

Furthermore, insight also develops through real-life experiences coupled with constructive feedback. This was not possible during hospitalisation, as participants were not allowed to leave the hospital during their admission and experienced the hospital as an island, far removed from stressors. Therefore, participants only developed in-depth understanding of their problems after discharge, as that was when they came face-to-face with challenges. Results of a study by Nikendei et al. (39) found that one of the main advantages of day hospital attendance compared to in-patient treatment was the effective carry-over of learning experiences, which benefit the development of insight. Resonating with the findings of the current study, in-patient admissions on the other hand did not support the transfer of insight to the same extent.

Secondly, participants' reluctance to acknowledge the implications of being diagnosed with MDD could have contributed to their unrealistic expectations regarding recovery. Although accepting the diagnosis of a psychiatric illness is difficult, it has been shown to contribute to recovery (136). Acceptance involves a process, which includes acknowledging the illness and taking steps to structure one's life accordingly (197). Unrealistic expectations might therefore be an indication that participants in this study have not yet come to terms with their diagnosis at the point of discharge.

5.2.2.2 Restricted sense of responsibility

Taking responsibility and engaging in an active approach in managing MDD has been found to contribute towards one's recovery (140). Specifically, a qualitative study by Chambers et al. (138) found that taking control and actively deciding which strategies to employ are particularly helpful in the self-management of MDD. In the current study it emerged that the opposite also holds true: not taking ownership of recovery was perceived to have contributed to relapse and subsequent re-admission.

The value attached to personal responsibility differed greatly, when comparing participants' first admission to their re-admission. Consistent with a study by Skarsater et al, some participants struggled to take initiative in planning their lives after discharge (22). The reason for this could be linked to expectations relating to the medical model: it is the responsibility of your doctor and prescribed medication to make you better. It was only during re-admission, as insight improved, that meaning was attached to personal responsibility. It was only during their re-admission that they became more actively engaged in their transition process, by anticipating potential difficulties and putting an action plan in place to address it. Participants' greater sense of personal responsibility during their second admission are similar to findings by Nunstedt et al. (122), which show that having lived through a depressive episode contributes to the development of insight. Participants had a greater awareness of their own needs and could therefore identify more relevant coping strategies. It could be argued that they did not take responsibility for recovery after their first discharge as they lacked insight and in essence did not know what to take responsibility for.

In conclusion, challenges that participants experienced after discharge can partially be explained by the contrast between their expectations of recovery and the principles of the Recovery model. Participants struggled to regain control of their life situations after discharge. They lacked adequate insight, did not employ active self-management strategies and were faced with disappointment due to unrealistic expectations. These negative experiences were perceived to have contributed to their relapse and readmission to hospital.

Due to the nature of occupational therapy treatment principles, occupational therapists are well-suited to facilitate the implementation of the Recovery model in an inpatient unit. Although the development of coping skills can be seen as one of the recovery model principles (141), results of this current study indicate that not enough focus was placed on the ongoing nature of recovery.

5.2.3 I did not feel supported after discharge

The third key factor that participants perceived to have contributed to their relapse and readmission, was the experience of isolation after discharge. Findings illuminate the stark difference between the levels of support experienced during hospitalisation

and after discharge. Resonating with a study by Nolan et al. (70) which explored the experience of being discharged from inpatient psychiatric care, participants in this study described being faced with loneliness as a major challenge after discharge. This finding builds on previous evidence in which social isolation was highlighted by MHCUs as one of the main risk factors for readmission (115).

As described in Theme 2, participants in the current study attached meaning to the extent of which their recovery was supported within the context of hospitalisation. They valued the protective environment, social interaction as well as the availability support during hospitalisation. Similarly to findings by Nikendei et al. (39) who compared to effect of day clinic versus inpatient treatment for MDD, participants in the current study reported that hospitalisation fostered a sense of belonging, which contrasted starkly with their experiences of loneliness at home.

It can be posited that three factors contributed to the experience of loneliness after discharge: the absence of transitional discharge from hospital, the unfulfilled support needs of the support structure itself and loneliness due to participants' withdrawal.

5.2.3.1 The absence of transitional discharge

Participants' feelings of isolation after discharge was heightened by the abrupt transition from an acute hospital setting to participants' home environment, an experience which is described as difficult in the literature (39). Although participants knew in advance when they would be discharged and had the opportunity for follow-up treatment sessions with their psychologist and psychiatrist, discharge implied the complete end of structured support from other hospital staff and services, including occupational therapy. Participants experienced that they were thrown back into the "real world" too suddenly and perceived that they would have benefitted from a more gradual transition from hospital to home. Resonating with studies by Cunningham et al. (70) and Wells (198), participants in this current study were acutely aware of the differences between life in hospital and life at home. They found it difficult to settle back into their roles and responsibilities after discharge. They felt overwhelmed by the realities of their life-situations that awaited them. Highlighting the impact of psychiatric hospital admission, participants voiced the need to come to terms with their hospital experience and found it difficult to describe their experiences to loved ones. Similar to the findings of Nikendei et al. (39) participants suddenly found

themselves in an environment where no-one has lived through a similar experience and they were confronted with the feeling of not being understood. The challenges associated with an abrupt discharge were perceived to have contributed to relapse and readmission.

Importantly in the context of the current study, literature indicates that newly learnt skills are more successfully transferred to everyday life by MHCUs in a day clinic compared to those who have been admitted as inpatients (39). When MHCUs leave the treatment setting on a daily basis, they have the opportunity to reflect on the difficulties that they have encountered at home once they return to the treatment unit (40) and so develop new insight. Being admitted as an inpatient eliminates this possibility for feedback and makes the transition home at the point of discharge more challenging. Participants in the current study reported that they found it difficult to implement the coping skills that they have learnt in hospital which left them feeling ill-prepared to deal with stressors.

It is interesting to note the paradigm shift that occurred during hospitalisation. Participants described how the unknown became the known and the once feared hospital became a symbol of protection and belonging. On the other hand, the once familiar home-environment now became a place of vulnerability and distress. This is congruent with findings in the literature which highlight the sense of belonging that MHCUs experience as a major advantage of inpatient treatment, while at the same time it alienates them from their home environment making the discharge transition even more difficult (39).

The challenges that participants experienced about learning and applying new coping skills to their personal situations, highlight the importance of context in learning and recovery. When viewing transition in the light of the Model of Human Occupation, the reason for participants' difficult transition between hospital and home could be found in the environmental impact of each setting. Each environment provided different sets of "opportunity, support, demand and constraint" (199)(p21). Not just the physical differences in environments when comparing hospital to home, but also the emotional environment associated with each setting, contributed significantly to the type of experience participants encountered. Participants reported that they felt protected in hospital, but vulnerable after discharge. The hospital

routine facilitated the forming of new habits (e.g. social interaction and activity participation), which were difficult to sustain at home. It can be hypothesised that these two “worlds” were far removed from one another. What was learnt within the context of the one setting could not be generalised to the other. In the light of these findings, it can be argued that the divide between contexts should be bridged by allowing day or weekend leave for MHCUs, which would also facilitate a transitional discharge.

5.2.3.2 The support structure’s unfulfilled need for support

The support of family members or friends is crucial in the recovery of depression. As described in Theme 3, participants in the current study did not feel adequately supported after discharge. On the contrary, they felt blamed for being ill by their significant others, which included family members, friends as well as work colleagues. Similarly, a study by Y-Garcia et al. (149) found that MHCUs feel labelled, judged, lectured to and rejected by their support network, even when the support network attempted to offer support. This perception of insufficient support provided by significant others contributed to the lived experience of loneliness after discharge.

The three-fold reasons for significant others not being able to provide adequate support, could be hypothesised as the following: Lack of involvement in the treatment process, lack of insight in MDD and feeling burdened themselves. Each factor will now be discussed.

Firstly, lack of involvement of significant others in the treatment process posed a hindrance to providing support. In line with literature, participants acknowledged the importance of involving significant others in their treatment process, but were hesitant to involve their social networks themselves (200). Furthermore, the group therapy programme at the research setting did not allow significant others to attend group sessions at the time of this study. Similarly to a study by Priestly & McPherson (153) which explored the experiences of relatives providing care to a depressed individual, relatives of participants in the current study were left on their own to develop coping skills, without hospital-input. It can therefore be argued that relatives were summoned with a task that they were not equipped to undertake.

Lack of involvement of significant others resulted in the second factor affecting support, namely significant others' perceived lack of insight. To be able to offer optimal support, loved ones should have sufficient insight into the nature of MDD as well as their role in MHCUs' recovery. Some participants reported that loved ones tried to offer support, but that it became evident that they did not know how to offer appropriate support.

The poor insight of relatives also became evident in their view of psychiatric illness and hospitalisation. Major Depressive Disorder was perceived as merely an alteration in mood state and not as a disease. They had little understanding of the severity of the disorder and encouraged participants to, figuratively speaking, "pull up their socks". The necessity of hospitalisation was therefore questioned. Furthermore, significant others lacked insight into the nature of the treatment of MDD. Participation in craft, sport and relaxation activities, which are considered part of the occupational therapy treatment of MDD was associated with purely recreational activities and some family members perceived hospitalisation as "being on a holiday".

Based on above-mentioned misconceptions, participants reported that some family members did not want them to be admitted in the first place, whilst others pressurised participants to return home once admitted. It was as though the illness was not acknowledged. Furthermore, significant others expected instant and complete recovery at discharge that left participants feeling burdened by their expectations.

The third reason that emerged for significant others in the current study not being able to provide adequate support, is that they themselves might have felt burdened by their relative's psychiatric illness. Participants acknowledged that besides being aware of their own unmet support needs, their relatives might have been in need of support as well.

Resonating with a study by Skundberg-Kletthagen, Wangensteen, Hall-Lord & Hedelin (157) which explored the lived experiences of relatives of a MHCU diagnosed with MDD, participants in the current study acknowledged that their relatives had to compensate for their absence by taking over their roles and responsibilities, contributing to tension within the family (159). It should also be acknowledged that significant others have been through a challenging time in the

period leading up the hospital admission of participants, especially if there has been a suicidal gesture or threat, and might have experienced burden even before the diagnosis was made (151). Therefore, what participants experienced as poor support in the form of pressure to be discharged and being blamed for being ill, might be indicative of their support structure's justifiable unmet needs and resulting emotional difficulties.

Results indicate a need for a greater emphasis on the unmet needs for information and emotional support of relatives. As the literature indicates that care-giver burden can result in an increased risk for significant others to develop psychiatric disorders themselves (158), occupational therapy services should provide the opportunity for relatives to benefit from interventions. If not, their ability to provide support could be negatively impacted, resulting in a vicious circle.

5.2.3.3 Withdrawal from activities and relationships

While participants benefitted from participation in a range of different activities during hospitalisation, the lack of participation in meaningful activities after discharge resulted in isolation and was experienced to be detrimental to recovery.

The reason for non-participation in the current study appeared to be two-fold: lack of structure and the presence of depressive symptoms. Firstly, those participants who did not return to work after discharge did not anticipate the need for structured activity participation after discharge. It was only during their second admission to hospital that the value of participation in meaningful activities was acknowledged and participants took responsibility for structuring their time effectively. Secondly, the presence of depressive symptoms hampered activity participation, whether they were residual since the time of discharge or re-emerged once at home. As participation in structured activities not only facilitated social interaction, but also played a role in behavioural activation, the unavailability of activities after discharge or withdrawal from them contributed to feelings of loneliness and a depressed mood in participants in this study.

In addition to withdrawal from activities, participants reported that emotional isolation also contributed to feelings of loneliness after discharge. Although emotional support was available to some participants, they described how they withdrew emotionally

and struggled to make use of available support. Participants preferred not to disclose the fact that they have been admitted to a psychiatric hospital to people other than closest family and friends. One possible explanation for their reluctance to communicate, points to a deeply rooted issue in mental healthcare: the stigma associated with mental illness. Although participants in this current study did not experience overt stigmatizing responses from other people, they were vulnerable to the negative effects of self-perceived stigma. Similar to a study by Keogh, Callaghan & Higgins (106) participants were painfully aware of the negative associations that they and others hold regarding psychiatric hospitalisation. Participants reported that it was difficult to admit that they suffered from MDD. This self-perceived stigma had a negative influence on their self-esteem that led to further emotional and social withdrawal, as some participants reported feeling of lesser value when trying to re-integrate in their work and social circles after discharge.

The absence of meaningful communication can also be described as contributing to the experience of loneliness. Although participants acknowledged that it is difficult to receive support if you do not open up, they further reported difficulty with sharing even concrete, depression-related information with their significant others. In contrast to a Dutch study (140) in which MHCU's relished the opportunity to share information on depression with relatives, participants in the current study were reluctant to share information or their experiences of depression with others as it made them feel exposed and vulnerable.

Communication between themselves and their family members was stifled as many participants withdrew emotionally. Although participants expressed a longing to connect with those close to them, be it family or friends, they tended to internalise their true thoughts and feelings. This resonates with previous qualitative literature in which the realisation that you are the cause of suffering of significant others (as they have to compensate for your illness) and feelings of isolation can be so painful that MHCUs give up trying to be understood and tend to cut themselves off from others (119).

Reasons underlying participants' reluctance to be emotionally vulnerable can be linked to a resolve to prove to others that they have recovered, which made it difficult for them to reveal any self-perceived weakness. Not wanting to burden others with

their difficulties may have been another contributing factor to their silence. In addition, well-meant words of support by significant others were sometimes experienced as judgement or being lectured to. This echoes the findings of Garcia et al. (149), which found that even well-meant words of encouragement resulted in the experience of emotional pain and made MHCUs less likely to communicate about their depression, if the message is perceived as being negative. These findings highlight the complexity of communication related to MDD. In essence, the consequence of participants' withdrawal from activities and relationships was a compounding experience of isolation, which left them vulnerable for relapse and readmission.

In conclusion, findings revealed that participants were left with unmet needs at the point of discharge, making them vulnerable for relapse and readmission. Firstly, their ability to learn was compromised due the cognitive symptoms of MDD itself, the overwhelming experience of psychiatric hospital admission as well as a short hospital admission, limited the time available for learning to occur. Secondly, recovery was not seen as a process and participants did not anticipate any challenges in the future. However, they realised that their recovery journey had only just begun at the point of discharge and that they would need support to facilitate ongoing recovery. Lastly, participants voiced an unmet need for support after discharge. These challenges made them vulnerable for relapse and contributed to their readmission.

5.3 Support groups could be valuable

As discussed above, it can be concluded that participants perceived that they were discharged from hospital with unmet treatment needs. They felt that they would have benefitted from more time to learn coping skills that were applicable to their life stressors, after the acute phase of the illness. Once re-united with their home environments, most participants reported that they would have benefitted from support in applying newly-learnt coping skills, reflecting on the outcomes and dealing with stressful situations as they arise. The perceived absence of support after discharge was another unmet need that contributed to relapse and readmission.

The majority of participants indicated that they would value the attendance of a series of support group sessions post-discharge, which could serve as an extension

of the treatment gains that were achieved in hospital. From the findings it emerged that support groups could play a valuable role in recovery by providing a conducive learning environment, facilitating recovery as ongoing process and by providing an opportunity to experience connectedness. Interestingly, these findings reflect some of the healing factors in group therapy described by Yalom (201) which are employed as therapeutic factors in occupational therapy group work sessions.

Apart from the meanings that participants attached to the content of a support group, the venue of where the group was to be held was also perceived as being meaningful. Having the group in the familiar setting of the hospital, appeared to be a protective factor that would encourage attendance. During their re-admission, participants attached meaning to the hospital as a place of safety and reported preferring attending a group in this familiar environment after discharge. Although participants who lived in other provinces than Gauteng reported that it would be easier to attend a support group close to home, attending a group at the hospital would have been their first choice.

5.3.1 Support groups as creating a conducive learning environment

Participants described the need for being reminded of the coping strategies that have been introduced in hospital and to be equipped with new skills in order to cope with new stressors. This is in support of literature that shows that MHCUs with recurrent MDD have a need for continued learning regarding the disorder (138)(135) and value the opportunity to practice their skills in a group setting (134).

One possible explanation for this is that, as discussed in 5.2.1.1, the time after discharge might be a more effective time for learning to take place and to employ a cognitive behavioural frame of reference, than in the acute phase of the illness. A support group could fulfil the need for effective learning which was not met at discharge, as the nature of MDD greatly hampers effective learning within the two weeks of hospitalisation. The learning experience would not have to compete with acute depressive symptoms, the onset of side effects of medication or the severely depressed emotional state MHCUs experience when first admitted. Furthermore, attending a support group after discharge could compensate for the shortfalls of short length of stay of only two weeks.

The sharing of information is regarded as one of the healing factors in group therapy (202). Participants also anticipated this to contribute to their recovery, as they saw support groups as an opportunity where one can learn from the experiences of others and also share what they have learnt with others. By doing so, the insight that they had gained through their experience with depression could benefit others as well. This expression of altruism also constitutes a healing factor that added to the therapeutic value of support groups (202).

Furthermore, support groups could also serve as a learning environment for significant others. As discussed earlier in this chapter, a potential barrier to providing support was that family members did not always acknowledge the severity and impact of MDD. This resulted from their poor insight relating to the disorder. Furthermore, family members did not always know how to offer appropriate support, despite their attempts and good intentions. A support group could improve the insight of family and friends into MDD and teach them the necessary skills in order to provide appropriate support. It could also make family members aware of their own emotional needs so that their mental wellbeing would not be neglected.

5.3.2 Support groups as means of supporting ongoing recovery

As discussed in 5.2.2 “Life was not was I expected it to be after discharge”, recovery is an ongoing process which aims to improve and sustain occupational functioning (131). Participants voiced the need for ongoing support after discharge and anticipated that a support group would help them cope with life. It could be suggested that a support group would incorporate Recovery theory principles by supporting MHCUs to effectively cope with the difficulties associated with their illness on an ongoing basis.

One aspect of the recovery process that participants found particularly difficult was the unsupported transition between hospital and home. Participants reported that they would value support with smoothing this transition. Guidance with adapting to life at home and structuring their lives was thought by participants to be helpful topics to address in a series of support group sessions. This is in support of literature that show that support group attendance is helpful in coping with transitional stressors (175).

Apart from the need for continued learning about MDD, participants also voiced the need for support in applying this information to everyday challenges as they arise. They found applying coping skills after discharge more difficulty than they thought it would be, and anticipated that a support group would help them to establish a clearer connection between theory and “real” life. Support in coping with current life stressors is of importance, as the literature indicates that MHCUs attribute current life stress as a predominant cause of their depression (113). Findings are therefore in support of literature that suggest that peer support interventions can decrease depressive symptoms that peer support should be included in recovery-orientated treatment of MDD (163).

The literature also indicates that regular group attendance provides structure (133) and a knowledgeable environment in which the signs of relapse can be detected (170), which has been found to assist with recovery. However, these were not factors that participants in the current study attached meaning to.

5.3.3 Support groups as a place to experience connectedness

Participants reported that they attached great value to the social interaction that they had experienced whilst in hospital. However, they perceived that it was as though the “safety net” of all the readily available support in hospital was pulled from beneath them at the point of discharge and ironically that was the point that participants identified where they needed support the most.

The participants described the experience of “being in the same boat” as others as valuable, which is a construct described as “universality” by Yalom (201). Participants reported that this sense of belonging amongst participants whilst in hospital was experienced as beneficial to their recovery. Participants felt understood by others who had had similar experiences and experienced a sense of connectedness to them. Participants described how they felt isolated from others on discharge and were hesitant to share information relating to their illness, resulting in deep feelings of loneliness. This is in line with literature that indicates that MHCU’s are reluctant to share their personal experiences with someone who does not have first-hand experience of the condition themselves (119).

In alignment with the study by Skarsater & Willman (147) which explored the concept of transition in the recovery process, participants in the current study expressed the need for contact with others in a similar situation after discharge. They anticipated that a support group would facilitate the sharing of experiences in an accepting environment. The importance of acceptance and empathy is echoed by Behler (134), who adds the positive factor of having one's experience of depression normalised by others in the group. Sharing experiences in a support group setting paves the way for the experience of another healing factor that participants anticipated: the instillation of hope. Participants expected to be encouraged by seeing how fellow-sufferers cope with life's challenges. This is in support of a study by Falk-Kessler, Momich & Perel (203) which found that MHCUs highly valued the instillation of hope in occupational therapy groups.

*S*upport groups could therefore counter-act the negative experience of loneliness and isolation after discharge by providing a safe environment in which experiences can be shared.

In conclusion, all of the positive meanings that were attached to support group attendance could be linked to one central function of support groups: to address remaining or continuous treatment needs at the time of discharge. The benefits of support attendance that emerged in the current study echo the earlier findings of Dennis (175), that state that support groups decreases isolation, buffers against the impact of stressors and increases the sharing of information.

5.3.4 Support groups as a place of emotional vulnerability

Although the majority of participants attached positive meanings to the possible attendance of support groups, two of the participants voiced their reluctance to attend. The reason for this could be that sharing personal information, with the reciprocal aspect of listening to the shared experiences of others, represented a degree of emotional vulnerability that participants could not bear. Their hesitation highlights the fragile interactions that take place in occupational therapy group work, as well as the importance of establishing trust and cohesion during the early stages of group therapy. Although no literature was found relating to the negative experiences of face-to-face support groups for MDD, negative experiences relating to internet support groups have been described in literature. However, the negative

experiences that were described related to comparing oneself unfavourably with others in the group, receiving unhelpful advice and missing a sense of connection which were not reported by the participants in the current study (172).

5.4 Implications for service delivery in occupational therapy

Occupational therapists have a key role to play in equipping MHCUs with specific tools that they need to protect themselves against recurrence of MDD (30). Results call for a greater recovery-orientated approach, in which occupational therapists need to advocate for recovery that is not just symptom-driven, but also occupation-driven. Although the installation of hope is one of the most therapeutic factors in occupational therapy group work (203), the recurring nature of MDD should be acknowledged during therapy in order for MHCUs to have a realistic expectation of recovery.

Results highlight the complex nature of the acute phase of MDD, which challenge occupational therapists to re-think the current model of in-hospital service delivery. As emphasis was placed on the attendance of psycho-educational groups to improve coping skills, when participants were not ready to comply with the cognitive demands of group work. Group participation should therefore be graded to accommodate the various stages of recovery, accommodating both “doing therapy” and “talking therapy”, with activity-based groups being offered initially and life-skill based groups towards the end of admission. When coping skills are discussed during thematic groups, the focus should be on applying the strategies on each MHCU’s personal situation.

Results highlighted the importance of problem-solving skills as mechanism to enhance coping, as participants found it difficult to problem-solve after discharge and as a result felt overwhelmed when faced with stressors. Goal setting and activity scheduling also appear to have been a neglected aspect of treatment, as participants lacked concrete goals for the period following discharge in order to re-engage with meaningful occupations and struggled to make good use of their time. Occupational therapy group work sessions should therefore place emphasis on goal setting and problem-solving skills.

Results also challenge occupational therapists to think beyond the scope of traditional in-patient treatment and to extend services to include the period after discharge and to include relatives in some aspects of the treatment programme. Results call upon the advocacy role of occupational therapists to negotiate with the hospital management and medical schemes in order to secure funding to enable the above, as well as advocate for the introduction of day leave for MHCUs to facilitate a transitional discharge from hospital.

5.5. Conclusion

Recovery from MDD is a complex process and ongoing journey. This study has shed some light on the challenges that MHCUs experience during hospitalisation as well as after discharge that hamper recovery and contribute to relapse. These findings can be generalised to other MHCUs diagnosed with MDD and treated in private psychiatric hospitals with similar treatment programmes to that of the hospital described in this study.

Participants could not make the most of their time in hospital, as their ability to learn was compromised by the overwhelming emotional experience of psychiatric hospitalisation, the cognitive effects of MDD as well as the implications of a short length of stay in hospital due to managed healthcare. When participants' process of recovery was viewed in the light of the Recovery model, it emerged that they had unrealistic expectations regarding their recovery journey. Participants expected complete recovery at the time of discharge, but took little responsibility for it as their insight was not yet well-developed. The final challenge that participants encountered was feelings of extreme loneliness and isolation after discharge. They struggled with the abrupt transition from hospital to home and felt unsupported by their significant others. However, it emerged that their support structure also had unmet support needs of their own, which left them with limited emotional resources to support participants. In addition, participants withdrew from activities and relationships which compounded their feelings of loneliness, due to perceived stigma and the re-occurrence of depressive symptoms.

The majority of participants indicated that they would want to attend a support group after discharge. The hospital where participants have been admitted emerged to be the preferred location, as participants associated it with the sense of safety and

belonging that they had experienced during admission. Participants anticipated that a support group would provide the opportunity to learn new skills, reflect on those that they have learnt in hospital and help them to apply coping skills to their everyday situations. Participants realised that they would benefit from ongoing support as their journey to recovery stretched far beyond the point of discharge. Support group attendance would also counteract feelings of isolation and loneliness as it provides a safe environment in which to experience a sense of connectedness once again.

It can be concluded that hospitalisation should only be seen as a part of the treatment plan for MDD and that recovery should be embraced as an ongoing journey. Mental Health Care Users face several challenges during and after admission, in which occupational therapy can play a valuable role.

CHAPTER 6
CONCLUSION

6.1 Introduction

This chapter summarises the main findings of this study. Limitations of this study are acknowledged and reflected upon. Lastly, recommendations for occupational therapy practice in private acute mental health care are made as well as suggestions for further research.

6.2 Main findings

The aim of this qualitative study was to explore the lived experiences of MHCUs diagnosed with MDD following discharge after a short period of hospitalisation and their perceptions of challenges that could lead to readmission within six months. The study also aimed to explore the perceived value of occupational therapy support groups after discharge.

Three themes emerged describing the challenges that MHCUs experienced. These were: “The inability to fully benefit from hospitalisation”; “Life was not what I expected it to be after discharge”; and “I did not feel supported after discharge”. In the fourth and final theme participants reflected on the possible benefits of support group attendance post-discharge and concluded that “Support groups could be valuable”.

The first theme described the various challenges that participants faced during their first hospital admission, which prevented them from making the most of their time in hospital. Subjective feelings of guilt as they perceived themselves not to be as sick as others, not being able to fulfil their occupational roles and responsibilities while in hospital, coupled with pressure from family members to return home, as well as the internal and external stigma of being in a psychiatric hospital, prevented participants from focussing on their own treatment needs. Furthermore, restrictions in medical scheme financing resulted in premature discharge as funds were depleted. Lastly, participants perceived that they could not fully benefit from the occupational therapy treatment programme which introduced new coping skills in a series of thematic groups aimed at effective coping after discharge. For successful implementation it

was important that participants engaged with and were able to absorb the information. However, participants struggled with reduced concentration which impaired their ability to learn. They were also overwhelmed by the stigma of psychiatric hospitalisation which restricted participation and subsequently resulted in lost treatment time. Not being able to fully benefit from the hospitalisation contributed to readmission as participants were not well-equipped to deal with stressors that awaited them after discharge.

The second theme indicated that participants perceived the end of hospitalisation to equate to complete recovery. They did not view recovery as an ongoing process, held unrealistic expectations of what life after discharge should have been like and felt overwhelmed by the reality of "real life" that they were faced with after discharge. Ironically, most support was withdrawn upon discharge at the point when MHCUs were at their most vulnerable and support was therefore needed most. The transition from hospital to home was experienced as being too abrupt, leaving them vulnerable and lonely in a harsh world. Participant accounts portrayed a sense of disillusionment as they battled the same stressors that precipitated their admission, while struggling to implement the coping skills that they have heard but not mastered. Furthermore, symptoms of depression that have not resolved completely or that re-emerged after discharge made coping with day-to-day life even more challenging.

Thirdly, life after discharge was described as an isolating experience in which participants did not feel supported. They were painfully aware of the stigma associated with depression and found it difficult to disclose their feelings as they attempted to seek support. Furthermore, people in their support network lacked knowledge regarding depression which hampered their efforts to provide meaningful support.

In addition to the challenges described above that participants experienced, the meanings that participants attached to the attendance of support groups after discharge were also explored. Participants spoke highly of the anticipated value that support groups might add. It emerged that participants perceived that support groups could fulfil the unmet needs which were described as challenges in the first three themes of this study. They perceived that a support group could bridge the gap

between unlimited support in hospital and the lack thereof after discharge by creating a nurturing space in which experiences could be shared to counteract the loneliness that participants experienced after discharge. Furthermore, support groups could provide an opportunity for reflection and re-learning when participants attempt to implement coping skills and can therefore play a role in improving the transferability of skills from hospital to home.

6.3 Limitations of the study

As the researcher engaged in a process of reflection, limitations in this study became evident which need to be acknowledged.

The sample used in this study cannot be considered representative of the South African population and results can therefore not be generalised to public mental health hospitals. The geographical location of the Private Psychiatric Hospital is in an affluent part of the city. As the hospital is a private institution, it predominantly attracts MHCUs from higher socio-economic backgrounds, who belong either to a medical scheme or with adequate financial resources to fund their treatment. Furthermore, as the majority of psychiatrists were Afrikaans-speaking at the time of data collection, the mother tongue of MHCUs who chose to be admitted to the hospital also tended to be Afrikaans and therefore the results are linked to a specific cultural group. This limited the extent to which the findings can be generalised to other private hospitals which provide services to other cultural groups. In addition, no demographic information other than gender was collected, limiting the profile of participants.

It has to be acknowledged that the researcher is not an expert translator and in the process of translating significant statements from Afrikaans to English, certain nuances and syntax might have been lost.

The influence of depressive symptoms on the interview process should also be acknowledged. As participants were interviewed shortly after hospital readmission, therefore in the midst of a depressive episode, the influence of impaired cognition became evident during data analysis. Participants had difficulty expressing themselves, strayed from the topic at times and did not finish sentences. As a novice researcher, and also in an attempt not to steer interviews in a specific direction other

than the decided-upon interview schedule, participants might not have been prompted enough to elaborate or clarify their responses. Therefore, their accounts might not have been explored in enough detail, limiting the richness of their descriptions which could potentially have shed more light on the phenomenon.

6.4 Recommendations

6.4.1 Recommendations for occupational therapists

Firstly, one could argue that hospitalisation should not been seen as a complete treatment process, especially with a short duration of two weeks. Occupational therapists need to advocate for more effective treatment opportunities at the right time and at a reasonable cost. Also, as depressive symptoms tend to have subsided at the point of discharge, MHCUs would be more able to absorb and apply information in order to cope more effectively and would be able to take greater responsibility for managing the illness. The scope of the occupational therapy programme could potentially be broadened to extent to the period beyond discharge by offering occupational therapist-led support groups. This would be relevant as the post discharge period is when MCHUs are faced with stressors relating to their occupational, social, environmental contexts that maintain depression and only then do they develop a deeper understanding of their occupational treatment needs.

Secondly, depression should be acknowledged as a “systemic illness” in which the occupational therapist has a responsibility not only towards the MHCU diagnosed with MDD, but also to the occupational environment in which the MHCU functions, including family and work relations. The inclusion of significant others in treatment can be accomplished by inviting them to open occupational therapy group sessions. The purpose should be twofold: To improve their insight regarding MDD as illness as well as providing them with much needed support, as living with someone diagnosed with MDD can be a challenge in itself.

Lastly, learning opportunities offered to MHCUs during hospitalisation should be maximised, by synchronising activity requirements with depressive symptom severity. Groups requiring higher cognitive functions should therefore be attended at a later stage in admission, or after discharge in a support group setting, when symptoms have improved to such an extent that effective learning can take place.

6.4.2 Recommendations for future research

A similar study to this one is recommended in a more diverse cultural and socio-economic setting that would be more representative of the South African population. A study in a public mental health facility might highlight different challenges and unmet needs to the results of the current study.

As this study reported on the perceived value of support group attendance, future research is necessary to evaluate the effectiveness of support group attendance. A qualitative approach is suggested to explore the experiences of MHCUs within a support group setting while a quantitative approach can be employed to investigate the influence of attendance on coping ability and what the influence of support group attendance would be on readmission rates. Furthermore, the needs of significant others relating to a relative diagnosed with MDD should be explored with the aim of developing an educational programme to improve their insight and facilitate the giving of meaningful support.

6.5 Concluding the research

This study aimed to contribute to an improved understanding of MHCUs' needs after discharge by shedding light on their difficult journey to recovery from MDD. Awareness of as well as addressing unmet needs could potentially decrease the number of readmissions and the subsequent burden on the mental health care system. Most importantly though, addressing the needs of MHCU's diagnosed with MDD could help them to cope more effectively with this debilitating disease and by doing so instil hope that life is worth living.

REFERENCES

1. Total-cost-of-ownership. Dictionary, Encyclopedia and Thesaurus - The Free Dictionary. TheFreeDictionary.com. 2012.

2. Pendleton HM. Pedretti's Occupational Therapy, Practice skills for physical dysfunction. In: 7th ed. St. Louis, Missouri: Elsevier Mosby; 2013. p. 450.

3. Howe MC, Schwartzberg S. A functional approach to group work in occupational therapy. In: Third. Lippincott Williams & Wilkins; 2001. p. 29.

4. Frank E, Prien RF, Jarrett RB, Keller MB, Kupfer DJ, Lavori PW, et al. Conceptualization and rationale for consensus definitions of terms in major depressive disorder. Remission, recovery, relapse, and recurrence. Arch Gen Psychiatry. 1991;48(9):851–5.

5. Rush JA, Kraemer HC, Sackeim HA, Fava M, Trivedi MH, Frank E, et al. Report by the ACNP Task Force on response and remission in major depressive disorder. Neuropsychopharmacology. 2006;31(9):1841–53.

6. World Health Organization. The Global Burden of Disease: 2004 update. 2004 Updat. 2008;146.

7. WHO. Depression, a global public health concern. WHO Dep Ment Heal Subst Abus. 2012;1–8.

8. Andrade L, Caraveo-Anduaga JJ, Berglund P, Bijl R, De Graaf R, Vollebergh W, et al. The epidemiology of major depressive episodes: Results from the International Consortium of Psychiatric Epidemiology (ICPE) Surveys. Int J Methods Psychiatr Res. 2003;12(1):3–21.

9. Kessler RC, Bromet EJ. The epidemiology of depression across cultures. Annu Rev Public Health. 2013;34:119–38.

10. Tomlinson M, Grimsrud AT, Stein DJ, Williams DR, Myer L. The epidemiology of major depression in South Africa: results from the South African stress and health study. S Afr Med J. 2009;99(5 Pt 2):367–73.

11. Stein DJ, Seedat S, Herman A, Moomal H, Heeringa SG, Kessler RC, et al. Lifetime prevalence of psychiatric disorders in South Africa. Br J Psychiatry. 2008;192:112–7.

12. Freeman CP, Joska JA. Dealing with major depression in general practice. South African Fam Pract. 2013;55(4):319–25.

13. Andersson LM, Schierenbeck I, Strumpher J, Krantz G, Topper K, Backman G, et al. Help-seeking behaviour, barriers to care and experiences of care among persons with depression in Eastern Cape, South Africa. J Affect Disord. 2013;151(2):439–48.

14. Mall S, Lund C, Vilagut G, Alonso J, Williams DR, Stein DJ. Days out of role due to mental and physical illness in the South African stress and health study. Soc Psychiatry Psychiatr Epidemiol. 2014;50(3):461–8.

15. Goldston K, Baillie AJ. Depression and coronary heart disease: A review of the epidemiological evidence, explanatory mechanisms and management approaches. Vol. 28, Clinical Psychology Review. 2008. p. 289–307.

16. Gan Y, Gong Y, Tong X, Sun H, Cong Y, Dong X, et al. Depression and the risk of coronary heart disease: a meta-analysis of prospective cohort studies. BMC Psychiatry. 2014;14(1):7.

17. Mezuk B, Eaton WW, Albrecht S, Golden SH. Depression and type 2 diabetes over the lifespan: A meta-analysis. Diabetes Care. 2008;31(12):2383–90.

18. Lépine JP, Briley M. The increasing burden of depression. Neuropsychiatr Dis Treat.

2011;7(SUPPL.):3–7.

19. Kamenov K, Caballero FF, Miret M, Leonardi M, Sainio P, Tobiasz-Adamczyk B, et al. Which Are the Most Burdensome Functioning Areas in Depression? A Cross-National Study. Front Psychol. 2016;7:1342.

20. LaRosa AC, Glascoe FP, Macias MM. Parental Depressive Symptoms: Relationship to Child Development, Parenting, Health, and Results on Parent-Reported Screening Tools. J Pediatr. 2009;155(1):124–8.

21. Sweeney S, MacBeth A. The effects of paternal depression on child and adolescent outcomes: A systematic review. Vol. 205, Journal of Affective Disorders. 2016. p. 44–59.

22. Skärsäter I, Baigi A, Haglund L. Functional status and quality of life in patients with first-episode major depression. J Psychiatr Ment Health Nurs. 2006;13(2):205–13.

23. IsHak WW, Greenberg JM, Balayan K, Kapitanski N, Jeffrey J, Fathy H, et al. Quality of life: the ultimate outcome measure of interventions in major depressive disorder. Harv Rev Psychiatry. 2011;19(5):229–39.

24. Berlim MT, McGirr A, Fleck MP. Can sociodemographic and clinical variables predict the quality of life of outpatients with major depression? Psychiatry Res. 2008;160(3):364–71.

25. Hawton K, Casañas i Comabella C, Haw C, Saunders K. Risk factors for suicide in individuals with depression: A systematic review. Vol. 147, Journal of Affective Disorders. 2013. p. 17–28.

26. Miret M, Ayuso-Mateos JL, Sanchez-Moreno J, Vieta E. Depressive disorders and suicide: Epidemiology, risk factors, and burden. Vol. 37, Neuroscience and Biobehavioral Reviews. 2013. p. 2372–4.

27. Gelenberg AJ. A review of the current guidelines for depression treatment. J ClinPsychiatry. 2010;71(7):e15.

28. Mura G. Exercise as an add-on strategy for the treatment of major depressive disorder: A systematic review. Vol. 19, CNS spectrums. 2014. p. 496–508.

29. Wisenthal A, Krupa T. Cognitive work hardening: A return-to-work intervention for people with depression. BMC Health Serv Res. 2014;

30. Richmond G. Occupational Therapy Evidence in Practice for Mental Health. In: Cathy Long,Jane Cronin-Davis DC, editor. 2nd ed. Chichester, UK: John Wiley & Sons Ltd; 2017. p. 165–89.

31. Piet J, Hougaard E. The effect of mindfulness-based cognitive therapy for prevention of relapse in recurrent major depressive disorder: a systematic review and meta-analysis. Vol. 31, Clin Psychol Rev. 2011. p. 1032–40.

32. Rhebergen D, Beekman ATF, de Graaf R, Nolen WA, Spijker J, Hoogendijk WJ, et al. Trajectories of recovery of social and physical functioning in major depression, dysthymic disorder and double depression: A 3-year follow-up. J Affect Disord. 2010;124(1–2):148–56.

33. Ishak WW, Mirocha J, James D, Tobia G, Vilhauer J, Fakhry H, et al. Quality of life in major depressive disorder before/after multiple steps of treatment and one-year follow-up. Acta Psychiatr Scand. 2015;131(1):51–60.

34. Solomon DA, Leon AC, Endicott J, Mueller TI, Coryell W, Shea MT, et al. Psychosocial impairment and recurrence of major depression. Compr Psychiatry. 2004;45(6):423–30.

35. Seemüller F, Meier S, Obermeier M, Musil R, Bauer M, Adli M, et al. Three-Year long-term outcome of 458 naturalistically treated inpatients with major depressive episode: severe relapse rates and risk factors. Eur Arch Psychiatry Clin Neurosci. 2014;264(7):567–75.

36. Hardeveld F, Spijker J, De Graaf R, Nolen WA, Beekman ATF. Prevalence and predictors of

recurrence of major depressive disorder in the adult population. Vol. 122, Acta Psychiatrica Scandinavica. 2010. p. 184–91.

37. American Occupational Therapy Association. Occupational Therapy Practice Framework: Domain and Process (3rd Edition). Am J Occup Ther. 2014;68(Supplement 1):S1–48.

38. Duncan M, Prowse C. Occupational Therapy with Mood Disorders. In: Crouch R, Alers V, editors. Occupational Therapy in Psychiatry and Mental Health. 5th ed. Wiley Blackwell; 2014.

39. Nikendei C, Haitz M, Huber J, Ehrenthal JC, Herzog W, Schauenburg H, et al. Day clinic and inpatient psychotherapy of depression (DIP-D): qualitative results from a randomized controlled study. Int J Ment Heal Syst. 2016;10:41.

40. Reynolds W, Lauder W, Sharkey S, Maciver S, Veitch T, Cameron D. The effects of a transitional discharge model for psychiatric patients. J Psychiatr Ment Health Nurs. 2004;11(1):82–8.

41. Sumsion T, Law M. A review of evidence on the conceptual elements informing client-centred practice. Can J Occup Ther. 2006;73(3):153–62.

42. Salmon N. Service Evaluation and the Service User: A Pluralistic Solution. Br J Occup Ther. 2003;66(7):311–7.

43. Sadock BJ., Sadock VC., Ruiz P. Kaplan and Sadock's Synopsis of Psychiatry Behavioral Sciences/Clinical Psychiatry. Kaplan and Sadock's synopsis of psychiatry: Behavioral sciences/clinical psychiatry (11th ed.). 2015. p. 356–9.

44. Rock PL, Roiser JP, Riedel WJ, Blackwell AD. Cognitive impairment in depression: a systematic review and meta-analysis. Psychol Med. 2014;44(10):2029–40.

45. Hasselbalch BJ, Knorr U, Hasselbalch SG, Gade A, Kessing LV. Cognitive deficits in the remitted state of unipolar depressive disorder. Neuropsychology. 2012;26(5):642–51.

46. Gillis I, Wilhelm K, Batchelor J, Burke D. Information processing speed remains low in school teachers a decade after recovery from depression. Vol. 29, International Journal of Geriatric Psychiatry. 2014. p. 1098–100.

47. Vanderhasselt MA, De Raedt R. Impairments in cognitive control persist during remission from depression and are related to the number of past episodes: An event related potentials study. Biol Psychol. 2009;81(3):169–76.

48. Lee RSC, Hermens DF, Porter MA, Redoblado-Hodge MA. A meta-analysis of cognitive deficits in first-episode Major Depressive Disorder. Vol. 140, Journal of Affective Disorders. 2012. p. 113–24.

49. Herzallah MM, Moustafa AA, Natsheh JY, Danoun OA, Simon JR, Tayem YI, et al. Depression impairs learning, whereas the selective serotonin reuptake inhibitor, paroxetine, impairs generalization in patients with major depressive disorder. J Affect Disord. 2013;151(2):484–92.

50. McIntyre RS, Cha DS, Soczynska JK, Woldeyohannes HO, Gallaugher LA, Kudlow P, et al. Cognitive deficits and functional outcomes in major depressive disorder: Determinants, substrates, and treatment interventions. Vol. 30, Depression and Anxiety. 2013. p. 515–27.

51. Snyder HR. Major depressive disorder is associated with broad impairments on neuropsychological measures of executive function: A meta-analysis and review. Psychol Bull. 2013;139(1):81–132.

52. Elliott R. Executive functions and their disorders. Vol. 65, British Medical Bulletin. 2003. p. 49–59.

53. Richards D. Prevalence and clinical course of depression: A review. Vol. 31, Clinical Psychology Review. 2011. p. 1117–25.

54. Burcusa SL, Iacono WG. Risk for recurrence in depression. Vol. 27, Clinical Psychology Review. 2007. p. 959–85.

55. Boerema AM, Kleiboer A, Beekman ATF, van Zoonen K, Dijkshoorn H, Cuijpers P. Determinants of help-seeking behavior in depression: a cross-sectional study. BMC Psychiatry. 2016;16:78.

56. Barney LJ, Griffiths KM, Jorm AF, Christensen H. Stigma about depression and its impact on help-seeking intentions. Aust N Z J Psychiatry. 2006;40(1):51–4.

57. Gili M, Vicens C, Roca M, Andersen P, McMillan D. Interventions for preventing relapse or recurrence of depression in primary health care settings: A systematic review. Vol. 76, Preventive Medicine. 2015. p. S16–21.

58. Gelenberg AJ. The Prevalence and Impact of Depression. J Clin Psychiatry. 2010;71(3):e06.

59. Ten Doesschate MC, Bockting CLH, Koeter MWJ, Schene AH. Prediction of recurrence in recurrent depression: A 5.5-year prospective study. J Clin Psychiatry. 2010;71(8):984–91.

60. O'Leary D, Costello F, Gormley N, Webb M. Remission onset and relapse in depression: An 18-month prospective study of course for 100 first admission patients. J Affect Disord. 2000;57(1–3):159–71.

61. Van Rijsbergen GD, Hollon SD, Elgersma HJ, Kok GD, Dekker J, Schene AH, et al. Understanding emotion and emotional scarring in recurrent depression. Compr Psychiatry. 2015;59:54–61.

62. Backs-Dermott BJ, Dobson KS, Jones SL. An evaluation of an integrated model of relapse in depression. J Affect Disord. 2010;124(1–2):60–7.

63. Post RM. Transduction of psychosocial stress into the neurobiology of recurrent affective disorder. Vol. 149, American Journal of Psychiatry. 1992. p. 999–1010.

64. Mitchell PB, Parker GB, Gladstone GL, Wilhelm K, Austin MP V. Severity of stressful life events in first and subsequent episodes of depression: The relevance of depressive subtype. J Affect Disord. 2003;73(3):245–52.

65. Lenze SN, Cyranowski JM, Thompson WK, Anderson B, Frank E. The cumulative impact of nonsevere life events predicts depression recurrence during maintenance treatment with interpersonal psychotherapy. J Consult Clin Psychol. 2008;76(6):979–87.

66. Hammen C. Generation of stress in the course of unipolar depression. J Abnorm Psychol. 1991;100(4):555–61.

67. McNaughton ME, Patterson TL, Irwin MR, Grant I. The relationship of life adversity, social support, and coping to hospitalization with major depression. J Nerv Ment Dis. 1992;180(8):491–7.

68. Rybakowski JK, Nawacka D, Kiejna A. One-year course of the first vs. multiple episodes of depression - Polish naturalistic study. Eur Psychiatry. 2004;19(5):258–63.

69. Kessing LV. Severity of depressive episodes during the course of depressive disorder. Br J Psychiatry. 2008;192(4):290–3.

70. Nolan P, Bradley E, Brimblecombe N. Disengaging from acute inpatient psychiatric care: A description of service users' experiences and views. J Psychiatr Ment Health Nurs. 2011;18(4):359–67.

71. Durbin J, Lin E, Layne C, Teed M. Is readmission a valid indicator of the quality of inpatient psychiatric care? J Behav Heal Serv Res. 2007;34(2):137–50.

72. Nurjannah I, Mills J, Usher K, Park T. Discharge planning in mental health care: An integrative review of the literature. Vol. 23, Journal of Clinical Nursing. 2014. p. 1175–85.

73. Lyons JS, O'Mahoney MT, Miller SI, Neme J, Kabat J, Miller F. Predicting readmission to the psychiatric hospital in a managed care environment: Implications for quality indicators. Am J Psychiatry. 1997;154(3):337–40.

74. Fisher WH, Geller JL, Altaffer F, Bennett MB. The relationship between community resources and state hospital recidivism. Am J Psychiatry. 1992;149(3):385–90.

75. Rao U, Chen LA. Characteristics, correlates, and outcomes of childhood and adolescent depressive disorders. Dialogues Clin Neurosci. 2009;11(1):45–62.

76. Kessing LV. Severity of depressive episodes according to ICD-I0: Prediction of risk of relapse and suicide. Br J Psychiatry. 2004;184(2):153–6.

77. IsHak WW, Greenberg JM, Cohen RM. Predicting relapse in major depressive disorder using patient-reported outcomes of depressive symptom severity, functioning, and quality of life in the individual burden of illness index for depression (IBI-D). J Affect Disord. 2013;151(1):59–65.

78. Fava M, Rush AJ, Alpert JE, Balasubramani GK, Wisniewski SR, Carmin CN, et al. Difference in treatment outcome in outpatients with anxious versus nonanxious depression: A STAR*D report. Am J Psychiatry. 2008;165(3):342–51.

79. Bukh JD, Andersen PK, Kessing L V. Rates and predictors of remission, recurrence and conversion to bipolar disorder after the first lifetime episode of depression - a prospective 5-year follow-up study. Psychol Med. 2016;46(6):1151–61.

80. Donisi V, Tedeschi F, Salazzari D, Amaddeo F. Pre- and post-discharge factors influencing early readmission to acute psychiatric wards: implications for quality-of-care indicators in psychiatry. Gen Hosp Psychiatry. 2016 Mar;39:53–8.

81. Tranter R, O'Donovan C, Chandarana P, Kennedy S. Prevalence and outcome of partial remission in depression. J Psychiatry Neurosci. 2002;27(4):241–7.

82. Paykel ES. Partial remission, residual symptoms, and relapse in depression. Vol. 10, Dialogues in Clinical Neuroscience. 2008. p. 431–7.

83. Pintor L, Gastó C, Navarro V, Torres X, Fañanas L. Relapse of major depression after complete and partial remission during a 2-year follow-up. J Affect Disord. 2003;73(3):237–44.

84. Mouchabac S, Ferreri M, Cabanac F, Bitton M. [Residual symptoms after a treated major depressive disorder: a survey among private psychiatrists]. Encephale. 2003;29(4 Pt 1):306–12.

85. Viinamäki H, Hintikka J, Tolmunen T, Honkalampi K, Haatainen K, Koivumaa-Honkanen H. Partial remission indicates poor functioning and a high level of psychiatric symptoms: a 3-phase 6-year follow-up study on major depression. Nord J Psychiatry. 2008;62(6):437–43.

86. McIntyre RS, O'Donovan C. The Human Cost of Not Achieving Full Remission in Depression. Vol. 49, Canadian Journal of Psychiatry. 2004.

87. Canadian Institute for Health Information. Depression in Ontario: What Predicts a First Mental Health Rehospitalization. Can Inst Heal Inf. 2010;

88. Bandura A. Self-efficacy: The exercise of control. 1st ed. Worth Publishers; 1997.

89. Gopinath S, Katon WJ, Russo JE, Ludman EJ. Clinical factors associated with relapse in primary care patients with chronic or recurrent depression. J Affect Disord. 2007;101(1–3):57–63.

90. Cronkite RC, Moos RH, Twohey J, Cohen C, Swindle R. Life circumstances and personal resources as predictors of the ten-year course of depression. Am J Community Psychol. 1998;26(2):255–80.

91. Haywood TW, Kravitz HM, Grossman LS, Cavanaugh JL, Davis JM, Lewis DA. Predicting the Revolving-Door Phenomenon Among Patients With Schizophrenic, Schizoaffective, and Affective-Disorders. Am J Psychiatry. 1995;152(6):856–61.

92. Ho SC, Chong HY, Chaiyakunapruk N, Tangiisuran B, Jacob SA. Clinical and economic impact of non-adherence to antidepressants in major depressive disorder: A systematic review. J Affect Disord. 2016 Mar 15;193:1–10.

93. Horesh N, Klomek AB, Apter A. Stressful life events and major depressive disorders. Psychiatry Res. 2008;160(2):192–9.

94. Roca M, Gili M, Garcia-Campayo J, Armengol S, Bauza N, García-Toro M. Stressful life events severity in patients with first and recurrent depressive episodes. Soc Psychiatry Psychiatr Epidemiol. 2013;48(12):1963–9.

95. Stroud CB, Davila J, Moyer A. The Relationship Between Stress and Depression in First Onsets Versus Recurrences: A Meta-Analytic Review. J Abnorm Psychol. 2008;117(1):206–13.

96. Monroe SM, Torres LD, Guillaumot J, Harkness KL, Roberts JE, Frank E, et al. Life stress and the long-term treatment course of recurrent depression: III. Nonsevere life events predict recurrence for medicated patients over 3 years. J Consult Clin Psychol. 2006;74(1):112–20.

97. Bockting CLH, Spinhoven P, Koeter MWJ, Wouters LF, Schene AH. Prediction of recurrence in recurrent depression and the influence of consecutive episodes on vulnerability for depression: A 2-year prospective study. J Clin Psychiatry. 2006;67(5):747–55.

98. Mundt C, Reck C, Backenstrass M, Kronmüller K, Fiedler P. Reconfirming the role of life events for the timing of depressive episodes. A two-year prospective follow-up study. J Affect Disord. 2000;59(1):23–30.

99. Skärsäter I, Langius A, Ågren H, Häggström L, Dencker K. Sense of coherence and social support in relation to recovery in first-episode patients with major depression: A one-year prospective study. Int J Ment Health Nurs. 2005;14(4):258–64.

100. Brown GW, Harris TO, Kendrick T, Chatwin J, Craig TKJ, Kelly V, et al. Antidepressants, social adversity and outcome of depression in general practice. J Affect Disord. 2010;121(3):239–46.

101. Leskela U, Rytsala H, Komulainen E, Melartin T, Sokero P, Lestela-Mielonen P, et al. The influence of adversity and perceived social support on the outcome of major depressive disorder in subjects with different levels of depressive symptoms. Psychol Med. 2006;36(6):779–88.

102. Thompson EE, Neighbors HW, Munday C, Trierweiler S. Length of stay, referral to aftercare, and rehospitalization among psychiatric inpatients. Psychiatr Serv. 2003;54(9):1271–6.

103. Fleurantin Y. The Effects of Stigma on Health Service Utilization and Health Outcomes among Adults with Chronic Depression. J New York State Nurses Assoc. 2013;44(2):40–5.

104. Farmer CS, Farrand P, O'Mahen H. "I am not a depressed person": How identity conflict affects help-seeking rates for major depressive disorder. BMC Psychiatry. 2012;12(1):164.

105. Lasalvia A, Zoppei S, Van Bortel T, Bonetto C, Cristofalo D, Wahlbeck K, et al. Global pattern of experienced and anticipated discrimination reported by people with major depressive disorder: a cross-sectional survey. Lancet. 2013;381(9860):55–62.

106. Keogh B, Callaghan P, Higgins A. Managing preconceived expectations: Mental health service users experiences of going home from hospital: A grounded theory study. J Psychiatr Ment Health Nurs. 2015;22(9):715–23.

107. Corrigan PW, Watson AC, Barr L. The Self–Stigma of Mental Illness: Implications for Self–

Esteem and Self–Efficacy. J Soc Clin Psychol. 2006;25(8):875–84.

108. Link BG, Struening EL, Neese-Todd S, Asmussen S, Phelan JC. Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. Psychiatr Serv. 2001;52(12):1621–6.

109. Owen-Smith A, Bennewith O, Donovan J, Evans J, Hawton K, Kapur N, et al. "When You're in the Hospital, You're in a Sort of Bubble.". Crisis. 2014;35(3):154–60.

110. Cutcliffe JR, Links PS, Harder HG, Balderson K, Bergmans Y, Eynan R, et al. Understanding the risks of recent discharge: The phenomenological lived experiences -"existential angst at the prospect of discharge." Crisis. 2012;33(1):21–9.

111. Prins MA, Verhaak PFM, Bensing JM, van der Meer K. Health beliefs and perceived need for mental health care of anxiety and depression - The patients' perspective explored. Clin Psychol Rev. 2008;28(6):1038–58.

112. Klein NS, van Rijsbergen GD, ten Doesschate MC, Hollon SD, Burger H, Bockting CLH. Beliefs about the causes of depression and recovery and their impact on adherence, dosage, and successful tapering of antidepressants. Depress Anxiety. 2017;34(3):227–35.

113. Hansson M, Chotai J, Bodlund O. Patients' beliefs about the cause of their depression. J Affect Disord. 2010;124(1–2):54–9.

114. Magaard JL, Schulz H, Brütt AL. What do patients think about the cause of their mental disorder? A qualitative and quantitative analysis of causal beliefs of mental disorder in inpatients in psychosomatic rehabilitation. PLoS One. 2017;12(1).

115. Mgutshini T. Risk factors for psychiatric re-hospitalization: An exploration. Int J Ment Health Nurs. 2010;19(4):257–67.

116. Dunlop BW, Kelley ME, Mletzko TC, Velasquez CM, Craighead WE, Mayberg HS. Depression beliefs, treatment preference, and outcomes in a randomized trial for major depressive disorder. J Psychiatr Res. 2012;46(3):375–81.

117. Hartdegen M, Gibson K, Cartwright C, Read J. Stressful events and circumstances reported by patients prior to being prescribed antidepressants. N Z Med J. 2017;130(1448):45–53.

118. Read J, Cartwright C, Gibson K, Shiels C, Magliano L. Beliefs of people taking antidepressants about the causes of their own depression. J Affect Disord. 2015;174:150–6.

119. Nystrom MES, Nystrom M. Patients' experiences of recurrent depression. Issues Ment Health Nurs. 2007;28(7):673–90.

120. Poslusny SM. Street music or the blues? The lived experience and social environment of depression. Public Health Nurs. 2000;17(4):292–9.

121. Danielsson L, Rosberg S. Depression embodied: an ambiguous striving against fading. Scand J Caring Sci. 2015;29(3):501–9.

122. Nunstedt H, Nilsson K, Skärsäter I, Kylén S. Experiences of major depression: individuals' perspectives on the ability to understand and handle the illness. Issues Ment Health Nurs. 2012 May 27;33(5):272–9.

123. Manning C, Marr J. "Real-life burden of depression" surveys - GP and patient perspectives on treatment and management of recurrent depression. Curr Med Res Opin. 2003;19(6):526–31.

124. Bockting CLH, Spinhoven P, Koeter MWJ, Wouters LF, Schene AH. Prediction of recurrence in recurrent depression and the influence of consecutive episodes on vulnerability for depression: A 2-year prospective study. J Clin Psychiatry. 2006;67(5):747–55.

125. Stroud CB, Davila J, Hammen C, Vrshek-Schallhorn S. Severe and nonsevere events in first onsets versus recurrences of depression: Evidence for stress sensitization. J Abnorm Psychol.

2011;120(1):142–54.

126. Stenhouse RC. “Safe enough in here?”: Patients’ expectations and experiences of feeling safe in an acute psychiatric inpatient ward. J Clin Nurs. 2013;22(21–22):3109–19.

127. Jones J, Nolan P, Bowers L, Simpson A, Whittington R, Hackney D, et al. Psychiatric wards: Places of safety? J Psychiatr Ment Health Nurs. 2010;17(2):124–30.

128. Desplenter FA, Laekeman GJ, Simoens SR. Following up patients with depression after hospital discharge: A mixed methods approach. Int J Ment Health Syst. 2011;5.

129. Davidson L. Recovery, self management and the expert patient -- changing the culture of mental health from a UK perspective. J Ment Heal. 2005;14(1):25–35.

130. Anthony WA. Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. Psychosoc Rehabil J. 1993;16(4):11–23.

131. Blank A, Hayward M. The role of work in recovery. Vol. 72, British Journal of Occupational Therapy. 2009. p. 324–6.

132. Stotland NL. Recovery from depression. Vol. 35, Psychiatric Clinics of North America. 2012. p. 37–49.

133. van Grieken RA, Kirkenier AC, Koeter MW, Schene AH. Helpful self-management strategies to cope with enduring depression from the patients’ point of view: a concept map study. BMC Psychiatry. 2014;14(1):331.

134. Behler J. Depression/bipolar peer support groups: Managing symptoms or promoting recovery. Union Institute and University; 2012.

135. Barney LJ, Griffiths KM, Banfield MA. Explicit and implicit information needs of people with depression: a qualitative investigation of problems reported on an online depression support forum. BMC Psychiatry. 2011;11(1):88.

136. Cunningham K, Wolbert R, Graziano A, Slocum J. Acceptance and Change: The Dialectic of Recovery. Vol. 29, Psychiatr Rehabil J. 2005. p. 146–8.

137. Van Grieken RA, Verburg HF, Koeter MWJ, Stricker J, Nabitz UW, Schene AH. Helpful factors in the treatment of depression from the patient’s, carer’s and professional’s perspective: A concept map study. PLoS One. 2016;11(12).

138. Chambers E, Cook S, Thake A, Foster A, Shaw S, Hutten R, et al. The self-management of longer-term depression: learning from the patient, a qualitative study. BMC Psychiatry. 2015;15(1):172.

139. Hansson M, Chotai J, Bodlund O. What made me feel better? Patients’ own explanations for the improvement of their depression. Nord J Psychiatry. 2012;66(4):290–6.

140. van Grieken RA, Kirkenier ACE, Koeter MWJ, Nabitz UW, Schene AH. Patients’ perspective on self-management in the recovery from depression. Heal Expect. 2015;18(5):1339–48.

141. Synovec CE. Implementing Recovery Model Principles as Part of Occupational Therapy in Inpatient Psychiatric Settings. Occup Ther Ment Heal. 2015;31(1):50–61.

142. Stickley T, Wright N. The British research evidence for recovery, papers published between 2006 and 2009 (inclusive). Part One: A review of the peer-reviewed literature using a systematic approach. J Psychiatr Ment Health Nurs. 2011;18(3):247–56.

143. Uebelacker LA, Eaton CB, Weisberg R, Sands M, Williams C, Calhoun D, et al. Social support and physical activity as moderators of life stress in predicting baseline depression and change in depression over time in the Women’s Health Initiative. Soc Psychiatry Psychiatr Epidemiol. 2013 Dec 5;48(12):1971–82.

144. Santini ZI, Koyanagi A, Tyrovolas S, Mason C, Haro JM. The association between social relationships and depression: A systematic review. Vol. 175, Journal of Affective Disorders. 2015. p. 53–65.

145. Nurullah AS. Received and provided social support: A review of current evidence and future directions. Am J Health Stud. 2012;27(3):173–88.

146. Antonovsky A. Health, stress, and coping. The Jossey-Bass social and behavioral science series. San Francisco: Jossey-Bass; 1979. p. 255.

147. Skarsater I, Willman A. The recovery process in major depression: an analysis employing Meleis' transition framework for deeper understanding as a foundation for nursing interventions. ANS Adv Nurs Sci. 2006;29(3):245–59.

148. Griffiths KM, Crisp DA, Barney L, Reid R. Seeking help for depression from family and friends: A qualitative analysis of perceived advantages and disadvantages. BMC Psychiatry. 2011;11(1):196.

149. Y-Garcia EF, Duberstein P, Paterniti DA, Cipri CS, Kravitz RL, Epstein RM. Feeling labeled, judged, lectured, and rejected by family and friends over depression: Cautionary results for primary care clinicians from a multi-centered, qualitative study. BMC Fam Pract. 2012;13(1):64.

150. Griffiths KM, Crisp DA, Barney L, Reid R, Highet N, Hickie I, et al. Seeking help for depression from family and friends: A qualitative analysis of perceived advantages and disadvantages. BMC Psychiatry. 2011;11(1):196.

151. Da Silva GDG, Jansen K, Barbosa LP, Branco J da C, Pinheiro RT, Magalhães PV da S, et al. Burden and related factors in caregivers of young adults presenting bipolar and unipolar mood disorder. Int J Soc Psychiatry. 2014;60(4):396–402.

152. Van Wijngaarden B, Koeter M, Knapp M, Tansella M, Thornicroft G, Vázquez-Barquero JL, et al. Caring for people with depression or with schizophrenia: Are the consequences different? Psychiatry Res. 2009;169(1):62–9.

153. Priestley J, McPherson S. Experiences of adults providing care to a partner or relative with depression: A meta-ethnographic synthesis. Vol. 192, Journal of Affective Disorders. 2016. p. 41–9.

154. Muscroft J, Bowl R. The impact of depression on caregivers and other family members: implications for professional support. Couns Psychol Q. 2000;13(1):117–134 18p.

155. Bottorff JL, Oliffe JL, Kelly MT, Johnson JL, Carey J. Surviving men's depression: women partners' perspectives. Health (London). 2014;18(1):60–78.

156. Radfar M, Ahmadi F, Fallahi Khoshknab M. Turbulent life: The experiences of the family members of patients suffering from depression. J Psychiatr Ment Health Nurs. 2014;21(3):249–56.

157. Skundberg-Kletthagen H, Wangensteen S, Hall-Lord ML, Hedelin B. Relatives of patients with depression: Experiences of everyday life. Scand J Caring Sci. 2014;28(3):564–71.

158. Van Wijngaarden B, Schene AH, Koeter MWJ. Family caregiving in depression: Impact on caregivers' daily life, distress, and help seeking. J Affect Disord. 2004;81(3):211–22.

159. Ahlström BH, Skärsäter I, Danielson E. Living with major depression: Experiences from families' perspectives. Scand J Caring Sci. 2009;23(2):309–16.

160. Pickett-Schenk SA, Bennett C, Cook JA, Steigman P, Lippincott R, Villagracia I, et al. Changes in caregiving satisfaction and information needs among relatives of adults with mental illness: results of a randomized evaluation of a family-led education intervention. Am J Orthopsychiatry. 2006;76(4):545–53.

161. Dixon LB, Lucksted A, Medoff DR, Burland J, Stewart B, Lehman AF, et al. Outcomes of a randomized study of a peer-taught Family-to-Family Education Program for mental illness. Psychiatr Serv. 2011;62(6):591–7.

162. Davidson L, Chinman M, Sells D, Rowe M. Peer support among adults with serious mental illness: A report from the field. Vol. 32, Schizophrenia Bulletin. 2006. p. 443–50.

163. Pfeiffer PN, Heisler M, Piette JD, Rogers MAM, Valenstein M. Efficacy of peer support interventions for depression: A meta-analysis. Gen Hosp Psychiatry. 2011;33(1):29–36.

164. Melling B, Houguet-Pincham T. Online peer support for individuals with depression: a summary of current research and future considerations. Psychiatr Rehabil J. 2011;34(3):252–4.

165. Houston TK, Cooper LA, Ford DE. Internet support groups for depression: a 1-year prospective cohort study. Am J Psychiatry. 2002;159(12):2062–8.

166. Griffiths KM, Mackinnon AJ, Crisp DA, Christensen H, Bennett K, Farrer L. The effectiveness of an online support group for members of the community with depression: a randomised controlled trial. PLoS ONE [Electronic Resour. 2012;7(12):e53244.

167. Jarchow SM. Women's Experiences Living with Depression. University of Wisconsin-Milwaukee; 2014.

168. Salzer MS, Shear SL. Identifying consumer-provider benefits in evaluations of consumer-delivered services. Psychiatr Rehabil J. 2002;25(3):281–8.

169. Verhaeghe M, Bracke P, Bruynooghe K. Stigmatization and self-esteem of persons in recovery from mental illness: the role of peer support. Int J Soc Psychiatry. 2008;54(3):206–18.

170. Behler J, Daniels A, Scott J. Depression / Bipolar Peer Support Groups : Perceptions of Group Members about Effectiveness and Differences from Other Mental Health Services Depression / Bipolar Peer Support Groups : Perceptions of Group. 2017;22(1):213–36.

171. Powell J, McCarthy N, Eysenbach G. Cross-sectional survey of users of Internet depression communities. BMC Psychiatry. 2003;3:1–7.

172. Dean J, Potts HW, Barker C. Direction to an Internet Support Group Compared With Online Expressive Writing for People With Depression And Anxiety: A Randomized Trial. JMIR Ment Heal. 2016 May 17;3(2):e12.

173. Vigod SN, Kurdyak PA, Dennis CL, Leszcz T, Taylor VH, Blumberger DM, et al. Transitional interventions to reduce early psychiatric readmissions in adults: Systematic review. Vol. 202, British Journal of Psychiatry. 2013. p. 187–94.

174. Bonsack, C; Golay, P; Manetti, S Gibellini; Gebel, S; Ferrari, P; Besse, C; Favrod, J; Morandi S. Transitional case management: Short-term community care intervention after psychiatric hospitalization. Vol. 160, Schweizer Archiv fur Neurologie und Psychiatrie. 2009. p. 246–52.

175. Dennis C. Peer support within a health care context: a concept analysis. Int J Nurs Stud. 2003;40(3):321–32.

176. Bonsack C, Golay P, Gibellini Manetti S, Gebel S, Ferrari P, Besse C, et al. Linking Primary and Secondary Care after Psychiatric Hospitalization: Comparison between Transitional Case Management Setting and Routine Care for Common Mental Disorders. Front psychiatry. 2016 Jun 2;7:96.

177. Guba EG, Lincoln YS. Competing Paradigms in Qualitative Research. Handb Qual Res. 1994;105–17.

178. Creswell JW. Qualitative inquiry & research design : choosing among five approaches. 3rd ed. SAGE Publications; 2013. p. 448.

179. De Vos AS, Delport C, Fouche C, Strydom H. Research at grass roots : for the social sciences and human services professions. Van Schaik; 2011. p. 547.

180. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health. 2000;23(4):334–40.

181. Verwijk E, Comijs HC, Kok RM, Spaans HP, Stek ML, Scherder EJA. Neurocognitive effects after brief pulse and ultrabrief pulse unilateral electroconvulsive therapy for major depression: A review. Vol. 140, Journal of Affective Disorders. 2012. p. 233–43.

182. Colaizzi PF. Psychological research as the phenomenologist views it. In: Vaile R, King M, editors. Existential phenomenological alternatives for psychology. New York: Oxford University Press; 1978. p. 48–71.

183. Whittemore R, Chase SK, Mandle CL. Validity in qualitative research. Qual Health Res. 2001;11(4):522–37.

184. Starks H, Trinidad SB. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. Qual Health Res. 2007;17(10):1372–80.

185. Angen MJ. Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. Qual Health Res. 2000;10(3):378–95.

186. Lincoln YS, Guba EG. Naturalistic inquiry. Newbury Park, California: SAGE Publications; 1985.

187. Chambers E, Cook S, Thake A, Foster A, Shaw S, Hutten R, et al. International update: I. Psychiatric rehospitalization following hospital discharge. J Affect Disord. NIH Public Access; 2011 Dec;11(3):22–7.

188. Brod M, Tesler LE, Christensen TL. Qualitative research and content validity: Developing best practices based on science and experience. Qual Life Res. 2009;18(9):1263–78.

189. Flick U. An introduction to qualitative research. In: 5th ed. SAGE Publications; 2014.

190. Neuman WL. Social research methods: qualitative and quantitative approaches. 4th ed. Boston: Ally & Bacon; 2000. p60 p.

191. Ritchie J, Lewis J. Qualitative Research Practice: A Guide for Social Science Students and Researchers. SAGE Publications. 2003.

192. Cowls J, Hale S. It's the activity that counts: what clients value in psycho-educational groups. Can J Occup Ther. 2005 Jun;72(3):176–82.

193. Tanaka S, Ishikawa E, Mochida A, Kawano K, Kobayashi M. Effects of Early-Stage Group Psychoeducation Programme for Patients with Depression. Occup Ther Int. 2015;22(4):195–205.

194. Tursi MFDS, Baes CVW, Camacho FRDB, Tofoli SMDC, Juruena MF. Effectiveness of psychoeducation for depression: a systematic review. Aust N Z J Psychiatry. 2013;47(11):1019–31.

195. Vogel S, Schwabe L. Learning and memory under stress: implications for the classroom. npj Sci Learn. 2016;1(April):16011.

196. Schwabe L, Wolf OT. Learning under stress impairs memory formation. Neurobiol Learn Mem. 2010;93(2):183–8.

197. Mizock L, Russinova Z, Millner UC. Acceptance of mental illness: core components of a multifaceted construct. Psychol Serv. 2014;11(1):97–104.

198. Wells DA. Management of early postdischarge adjustment reactions following psychiatric hospitalization. Vol. 43, Hospital & Community Psychiatry. 1992. p. 1000–4.

199. Kielhofner G. Model of Human Occupation: Theory and Application. 4th ed. Lupash EJ, Hauber MJ, editors. Baltimore: Lippincott Williams & Wilkins; 2008. p. 21.

200. Van Grieken RA, Beune EJAJ, Kirkenier ACE, Koeter MWJ, Van Zwieten MCB, Schene AH. Patients' perspectives on how treatment can impede their recovery from depression. J Affect Disord. 2014;167:153–9.

201. Yalom ID, Leszcz M. The Theory and Practice of Group Psychotherapy. 5th ed. New York: Basic Books; 2005. p. 1-12.

202. Ballinger B, Yalom I. Group therapy in practice. In: Comprehensive textbook of psychotherapy: Theory and practice. 1995. p. 189–204.

203. Falk-Kessler J, Momich C, Perel S. Therapeutic factors in occupational therapy groups. Am J Occup Ther Off Publ Am Occup Ther Assoc. 1991;45(1):59–66.

Appendix A: Interview Schedule

Thank you for agreeing to this interview and for giving up your time. As we've discussed earlier, I am busy with my Master's degree in Occupational Therapy. The topic of my study is to explore the challenges that patients face that could contribute to re-admission, as well as establishing the perceived value of support groups for patients after discharge. As you have agreed to take part in the study, I would like to ask you a couple of questions. Once again, information that you provide is confidential and will not be held against you in any way. You will only share as much as you feel comfortable to do. Your input will be much appreciated as it will help me to gain a better understanding of the situation.

Is that OK with you?

Thinking back to when you were discharged the first time: Did you feel equipped to face the challenges that waited for you?

Tell me about the challenges that you faced after discharge.

What do you think are the factors that lead to your re-admission?

Where did you receive emotional support after discharge?

Do you think that a support group for patients (that they attend after their discharge) could be beneficial to them? Why?

What do you think can be done here at the hospital to prepare patients so that they are more equipped to face the challenges after discharge?

Thank you for your input!

Appendix B: Ethical clearance

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Roestoff

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M061007**
PROJECT	Factors Affecting Re-Admission of Patients with Major Depressive Disorder and the Possible Value...
INVESTIGATORS	Ms N Roestoff
DEPARTMENT	Occupational Therapy Dept
DATE CONSIDERED	06.10.27
DECISION OF THE COMMITTEE*	APPROVED UNCONDITIONALLY

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 07.04.03 **CHAIRPERSON** .....
(Professors PE Cleaton-Jones, A Dhai, M Vorster, C Feldman, A Woodiwiss)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Mrs P de Witt

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix C: Denmar Specialist Psychiatric Hospital consent form



DENMAR
SPECIALIST PSYCHIATRIC HOSPITAL
SPESIALIS PSIKIATRIESE HOSPITAAL
(PTY) LTD. (EDMS) BPK. Reg. No. 80/04/PS1/07
PRO BONO PUBLICO

✉ 90609, Garsfontein 0042
507 Lancelot Rd, Garsfontein x16

☎ +27 (12) 993 2015/6, 998 6062/3/4/5
+27 (12) 998 7184
E-mail: denmar@mweb.co.za

3 April 2006

Ms Pat de Wit
Head: Department of Occupational Therapy
WITS Medical School
JOHANNESBURG
2000

Dear Madam

RE: NADIA ROESTORFF ST. NO 0418151/J

Ms Roestorff has for the past 4 years been a member of our staff and rendered services of highstanding quality.

She is enrolled with you for a MSc in Occupational Therapy.

Herewith permission is granted to Ms Roestorff to use the hospital and it's facilities for research and therapeutic purposes.

Kind Regards

LP STEENKAMP
SUPERINTENDENT: MEDICAL DIRECTOR

ISIBHEDLELA YEZOMETHA BEZIFO ZENGQONDO – SEPETJELE KGETHEGO YA SAEKHIATRIKI

Direkteure/Directors: E. Marx C.A. (SA) (Managing Director), J.H. Cloete, B.Comm (Hons) C.A. (SA), (Non-Executive Chairman), Dr. L.P. Steenkamp, Hons BSc Pharm MBChB, MFGP, MSAIP, MISCEH, FC Psych (CMSA), MMed (Psych) (End Forensic Psych), Dr M.J.J. Pretorius MBChB, MMed. (Psych) (Pret)

Appendix D: Participant consent form for participation in study

I am aware of the details of this study and wish to participate in it.

I agree to be interviewed by the therapist and to disclose information relating to my re-admission to Denmar Hospital. A maximum of three interviews will be held to ensure that enough information is obtained and each interview won't last longer than 45 minutes. All information will be treated with confidentiality. My psychiatrist may be informed about my participation in this study.

I understand that participation is voluntary and that I may withdraw at any time, without any negative consequence to me.

I am aware that my perspectives could be used in adapting the treatment programme for patients with Major Depression at Denmar Hospital.

_____ _____

Name Sign

Date: _____

_____ _____

Witness Sign

Date: _____

Appendix E: Participant consent form for electronic recording of interviews

I hereby agree that interviews may be taped electronically. The tapes will be held in safekeeping during the research project and will be destroyed after completion of the study to ensure participant confidentiality.

_____ _____

Name Sign

Date: _____

_____ _____

Witness Sign

Date: _____

Appendix F: Participant information sheet

Hi there!

My name is Nadia Roestorff and I'm an Occupational Therapist at this Private Psychiatric Hospital.

Many patients attend the therapeutic group programme whilst in hospital, where the focus is on acquiring life skills. The next challenge awaits patients once they leave hospital and return home. As Occupational Therapist, I am unaware of the progress that patients make and whether they are able to incorporate skills learnt in hospital, into their daily lives. I have encountered several patients who are re-admitted to the hospital but the challenges that they have faced are not known to me.

My study therefore aims to explore these challenges that could lead to re-admission and to establish whether support groups could be of value in addressing this problem. As you have been re-admitted, you are invited to participate in this study.

Interviews will be conducted with patients who are re-admitted to the hospital within 6 months of discharge, in order to gain insight into the factors that contributed to their re-admission. Their perceptions on the value of possible support groups for patients just after discharge will also be established. Interviews will not last for more than 45 minutes and a maximum of three interviews will be held.

Be assured that all the information gathered during this study will be treated with confidentiality. Your name will not be used on written records, instead a unique coding system will be used to ensure confidentiality. Interviews will be taped to ensure that no information is lost, the tapes will however be destroyed after the study has been completed. You are allowed to withdraw from the research at any time without it resulting in any negative consequence to you.

Your feedback is important, as it will help us to gain insight into the difficulties that patients with Major Depression face once they leave hospital. You could play a valuable role in expanding our knowledge regarding the effect the Major Depression has on people's functioning, so that we could create a more sufficient treatment programme.

Your assistance with this project will be much appreciated.

Kind regards, Nadia Roestorff.

Appendix G: Bracketing

It is necessary to reflect on my experiences relating to the research questions. My own perceptions are based on information that MHCUs with whom I worked shared with me during group sessions or individual conversations. It is also based on my observations during two groups that I facilitated at the hospital: the “Prepare for discharge” group and the “Depression” group, during which MHCUs were able to share their thoughts and worries. My experiences in these groups might have influenced my own perception of the research questions.

MHCUs are away from their usual role responsibilities during admission. All of their meals are provided, they choose to attend specific discussion groups, or craft and sport sessions. During this time they have the opportunity to reflect and rest, as many of them feel burnt-out when they are admitted. They feel motivated and ready upon discharge, only to be disillusioned and taken aback by the pressures that await them. It is almost as if they feel completely removed from their troubling situations when in hospital and find it daunting to return to the “real world”. They come to the sudden realisation that they have changed, but their life situations are mostly unchanged and that emotional work is still required in order to bring about change.

There might be a re-adjustment period after discharge, when MHCUs have to integrate the skills that they have learnt in hospital into their daily living. Some MHCUs anticipate that that would be easier said than done. Yet others feel so confident about the positive change in their mood that they don’t view it as necessary to set goals or plan strategies to facilitate a sound discharge, they assume that “all will be well” and leave hospital unprepared.

MHCUs also reflected upon the challenge of facing family, friends or work colleagues during or after admission. They often felt labelled as “mentally ill” which caused further emotional distress.

Some of them still seem vulnerable, as if they don’t feel ready to go but have to due to family or work pressures, or due to the financial constrictions imposed by their medical aid scheme. They don’t have the emotional resilience yet to effectively manage challenges they might face. Others might view the hospital as a “refuge”

and may be quite keen to be re-admitted, in an attempt to escape the challenges that they need to face.

Non-compliance with medication also seems to play a role. Once MHCUs feel that they are doing well emotionally, they stop taking anti-depressants which greatly increases the risk of relapse.

Attending post-discharge support groups at the hospital could be valuable. It is a familiar environment for MHCUs to return to and would not be as daunting venturing into an unknown setting. There would also be an established therapeutic relationship with staff as well a degree of cohesion between group members, which would contribute towards a conducive therapeutic environment.

It would be valuable for Occupational Therapists to facilitate the groups, as this would enable both facilitators and group members to reflect upon strategies that were suggested during admission and to monitor the effectiveness thereof. Groups will create the opportunity for group members to share information and ideas and to create a “safe space” where feelings could be expressed and explored. They could possibly feel encouraged after the session and be equipped with alternative strategies if necessary.

However, this could be difficult on a logistical level. Not all MHCUs live in or around Pretoria and would not be able to attend groups at the hospital. In general, MHCUs might not be able to take time off work and would therefore not be able to attend groups during the week. Occupational Therapists currently don’t work over the week-ends and would have to negotiate a new work rota with hospital management.

It is also queried whether MHCUs would remain motivated to regularly attend a support group, as a decrease in motivation is one of the features of a depressive illness. It is expected that MHCUs would have opposing ideas about the effectiveness of support groups post-discharge.