

EXPLORING AND DESCRIBING EXPERIENCES AND NEEDS OF FAMILY MEMBERS/SIGNIFICANT OTHERS OF MALE FORENSIC PATIENTS IN A SPECIALIST PSYCHIATRIC HOSPITAL.

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A Research Report submitted to the Faculty of Health Sciences, University of Witwatersrand, Johannesburg, in partial fulfilment for the degree of Master of Science (Nursing)

Johannesburg, June 2016

DECLARATION

I, Bashu Joseph Pule, declare that this Research Report is my own work except as indicated in the references and acknowledgements. It is submitted in partial fulfilment of the requirements for the degree of Master of Science (Nursing) at the University of the Witwatersrand, Johannesburg. It has not been previously published or submitted before for any degree or examination in this or any other university.

Signature

BJ PULE

.....day of.....2016

Protocol Number: M140235

DEDICATION

I would like to dedicate this study to the power of human mind and spirit, to my beloved family and friends. To the University of Witwatersrand, classmates, supervisors, Annalie Van Den Heever and Dr Gayle Langley for your patience and unwavering support. To the Hospital, my colleagues and participants without whose contribution and support this research study would have been impossible. I also dedicate this study to my late dad and my mother for their persistence and support for me to acquire some education.

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Thanks to my wife and family for allowing me splendid time of isolation and less bonding during my study, and thank you ever so much for your support, your patience and understanding. You are my strength and my joy.

LIST OF ABBREVIATIONS

MCHU- Mental Healthcare User

MDT-Multidisciplinary Team

WHO-AIMS- World Health Organization's "Assessment Instrument for Mental Health System"

WHO- World Health Organization

ABSTRACT

Family and caregivers play a vital role in providing support, care and assistance to forensic mental healthcare users. Family members of the forensic mental healthcare users often find their caregiving role stressful and suffer from significant stress and experience high levels of caregiver burden. Forensic patients need physical and emotional support from their family members to help them cope in the hospital, but the needs of those family members are often neglected when caring for the forensic patients in South Africa.

The objective of the study was to explore and describe the experiences and needs of family members/significant others of male forensic mental healthcare users in a specialist psychiatric hospital, and to recommend guidelines for the Psychiatric nurses to assist families of the forensic mental healthcare users to manage their stressful experiences.

A qualitative, exploratory, descriptive and contextual design was followed to achieve the aim and objectives of the study. Purposive sampling was used for sample selection. Two open-ended questions were asked in a semi-structured interview. The audio taped interviews were transcribed verbatim and analysed using thematic content analysis

Themes emerging were poor parental expectation, strained relationship with others, and the emotional and financial impact of caregiving. The families experienced emotional distress and lack of support by other family members as well as self-blame and strained relationships. These findings highlighted the need for inventions such as support groups and psycho-education for psychiatric nurses as well as families of forensic patients.

The findings are to be used to guide professional development, counselling and family therapy sessions that would assist the family members and also caregivers of the forensic patients to cope.

Key words: Experiences, Needs, Families, Forensic MHCU, Specialist Hospital.

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CHAPTER 1: INTRODUCTION AND BACKGROUND OF THE STUDY

1.1 INTRODUCTION

Forensic mental health care is carried out in a complex and involuntary situation. Forensic patients in this context have committed criminal offences under influence of serious mental disorder and are often cared for over a long period of time in institutions with high level of security (Horberg, Benzein, Erlingsson & Syren, 2015). This multifaceted and extremely complex situation has an extensive impact on the relationship and interaction between the patients in forensic psychiatric care and their families. These difficulties are further complicated by enforced separation between the forensic patient and the family, the geographic distance of the institutions, security routines, patient's past violent history and family member being the victim of the patient's violent act.

Family members of the forensic patients experience greater degree of care burden than families of ordinary patients. Burdened families of mentally ill patients often describe a sense of chaos and personal vulnerability associated with exhaustion and isolation (Lukens, Thorning & Lohrer 2004: 497). Levels of violence reported by families and caregivers, either as a victim or witnessing violent act of the patient, is higher and more dangerous for the family members than families of non-forensic patients (Horberg, Benzein, and Erlingsson & Syren 2015).

A South African study conducted by Nyathi & Sebit (2008:208) highlights the burden of mental illness on the entire family. Failure by other family members to share the family burden increases the stress and perceived lack of support. There are also possible heightened family emotions about their relative fuelled by guilt. Family members suffer emotional and even physical loss when a relative with serious mental illness is arrested for a criminal offence. Family unity can disintegrate when one of the members experience hardships in life.

The family burden is described by Kneisel & Trigobbof (2009: 820) as the difficulties and responsibilities that a family member who assumes the role of a caretaker for a mentally ill individual experiences. A caregiver is a family member who has been living with the patient, and has been closely involved in his activities of daily living, health care and social interaction for more than a year.

And the problems, difficulties or adverse effects on the lives of families including primary caregivers, are regarded as a burden (Swaroop, Ravi, Goud, Archana, Pius, Agrawal, John, & Jayaram 2013:29).

Caregiver burden in mental illness can either be objective or subjective or both. Objective burden is described as readily verifiable behaviour phenomenon such as negative patient symptoms, disruption of the caregiver's domestic routine, social activities and leisure, social isolation, financial and employment difficulties, (Swaroop et al 2013). Subjective burden is defined by the same author as emotional strain on the caregiver such as fear, sadness, anger, guilt, loss, stigma and rejection. These burdens impact upon the caretakers' health, causing disruptions in family routines, concern about the future, stigma, and an inability to cope as well as experiencing stress caused by mental health system itself.

In this study, the researcher explored how this already strained relationship between the mental health care users (MHCU) and their families are affected by the latest forensic admission and explored the experiences and needs of those families. For the purposes of the study, the term family member will be used inclusively of partner, significant other, closest relative or care giver.

1.2 BACKGROUND TO THE STUDY

The families of forensic patients constitute an important support system in the continuing care of the mentally ill persons, but the physical and emotional strain experienced by family and caregivers cannot be ignored (Swaroop et al, 2013). In any family, the behaviour of one family member affects the others. When a member of the family is adversely affected by life events other members become distressed. Many family members report that their caring role is stressful and their response to the patient is highly correlated with relapse (Tsang, Pearson & Yuen, 2006). The anecdotal discussions that the researcher and other health professionals had with families during their visits, revealed feelings of exclusion and neglect in the MHCUs' treatment and rehabilitation programmes.

Families caring for a mental care user who has been involved in criminal offence may have difficulty re-establishing a meaningful relationship with him. Family members are at times the victims of forensic mental healthcare users' violent attacks themselves. Violence and the social stigma often increase the stress levels of the families of forensic psychiatric patients. However, how family members experience and what their needs are when they are exposed to the forensic and legal system is seldom explored and this aspect is often neglected.

The experiences of family members of mentally ill relatives are largely unidentified and therefore not reported; these include stigmatized social interaction, high stress level and on-going caregiver burden. Services directed at supporting the family caregivers of persons with persistent mental illness have the potential to improve the outcome of both the caregivers and patients (Kneisel & Trigoboff, 2009: 821).

The hospital admission might be the decisive area for forensic patients, but relationships with their family members are of vital importance. Family support does not only provide forensic patients with physical support, but with emotional support such as love, affection and sense of belonging, identity and security. Neglecting the inclusion of family members in the treatment and rehabilitation programmes of forensic patients could delay their recovery and progress because they need physical and emotional support from their family members to help them cope in the hospital.

Providing holistic care to forensic psychiatric patients by psychiatric nurses means that all the people and services involved with the MHCU should work together towards an improved therapeutic programme.

It is posited that facilitation of family support of mentally ill persons who are hospitalised in forensic units will help to promote the patient's compliance with therapeutic programmes and reduce relapse and psychotic symptoms and improve knowledge and family relationships. Families believe that the burden they experience in caring for their mentally ill kin is underestimated by health care professionals; resulting in them feeling rejected, ignored and blamed (Kaas et al 2003 & Muhlbauer 2002, cited by Kneisel & Trigobbof 2009).

In cross section survey by Pusey-Murray and Miller (2013:114) among 344 mentally ill patients in Jamaica, it was found out that 46, 7% who adhered to treatment had family support and 27, 8% with poor adherence lacked family support. This suggests a significant relationship between treatment adherence and family support. Other factors cited by Pusey-Murray and Miller (2013:114) included among others, patient socio-demographic factors, illness characteristics, and medication factors such as side effects, the route and frequency of administration. The family caregiver's inability to be at home and to assist the mentally ill person with the activities of daily living further increased the self-blame and stress level.

Family members need information about the mental disorder in terms of diagnosis, treatment, prognosis as well as support from mental health care professionals in order to cope with their own needs in dealing with their mentally ill relative (Kneisel & Trigobbof 2009). Families need support to adjust and adapt, not only to their relative's mental illness but to come to terms with the fact that he has committed a serious criminal offence, one which warrants incarceration in a specialist mental health facility. Families should be involved in treatment planning of their ill relative, but an inability to understand the link between the criminal behaviour and mental illness could hinder their support. The family support in combination with adequate pharmacological therapy can reduce the relapse rate, hospitalisations, and family burden and improve relationship between family members and relatives with a psychiatric disability. Psychiatric nurses on the other hand are positioned to provide psycho education, family education, family therapies and supportive counselling to family members (Kneisel & Trigobbof 2009:800). Intervention by psychiatric nurses can greatly benefit forensic patients by reducing psychotic symptoms, preventing relapse episodes, improving social functioning and enhancing family relationships.

Listening to family members, providing information and referral to the community-based support services will help to strengthen family resources (Coursey et al. 2000a, 2000b, cite in Kneisel & Trigobbof, 2009). To enable psychiatric nurses to provide the above mentioned care and support, it is advised that they acquire the necessary advanced nurse practitioner skills and knowledge to assist the families of mentally ill forensic patients (Kneisel & Trigobbof 2009:19). Not only a lack of

support, but also the inability to assess and observe patients and their families, may exacerbate the existing problems that they have.

The aim of this study, therefore, was to elicit and describe the experiences and needs of family members in dealing with their forensic psychiatric relatives.

1.3 CLARIFICATION OF KEY CONCEPTS

1.3.1 Forensic patient/state patient

According to (Mental Health Act Section 42 Of Act no. 17 of 2002) “ SP” or state patient means that the person is detained in a secured forensic unit of a specialist hospital for treatment after being found not be criminally liable for the criminal act he committed by virtue of his mental incapacity and or was unable to understand the court proceedings.

1.3.2 Family member

Any representative of patient’s family or a significant other who is concerned about the patient, who reflects the characteristics or is able to share experiences of caring for the mentally ill forensic patient, either related to, caring for or visiting the patient detained in terms of Mental Health Act (Act no. 17 of 2002). The patient will be consulted as to who should be approached to act in this capacity, will be asked to nominate a person and consent will be sought from patient before obtaining any information from family members or significant others. Throughout this study the persons will be called family members.

1.3.3 Psychiatric nurse

A registered nurse has been trained in the field of Psychiatric Nursing to provide care treatment and rehabilitation to MHCUs (Mental Health Care Act No. 17 of 2002:10). In this case it refers to psychiatric nurses working with male adult forensic patients in the secured units/wards at the specialist hospital.

1.3.4 Mental health institution

According to the Mental Health Act (Act no. 17 of 2002:13) 'psychiatric hospital' means a health establishment where care, treatment and rehabilitation services for users with mental illness are provided. In this study 'mental health institution' will refer to a specialist hospital that provides care, treatment and rehabilitation services for male forensic patients with variety of mental disorders.

1.3.5 Experience

The Oxford English Dictionary (Soanes, Hawker & Elliott 2006:261) defines experience as the 'practical contact with and observation of facts or events and knowledge or skill gained over time. In this context, experience relates to families/relatives or significant others of male adult forensic patients in a specialist hospital. 'Experience' involves gaining knowledge by being personally involved in an event, situation or circumstances (Burns & Grove, 2011:17).

1.3.6 Needs

The perceived needs of family members whose member, relative or significant other is admitted to the hospital's secured forensic units.

1.4 PROBLEM STATEMENT

While working as a psychiatric mental health professional in a specialist forensic ward with male offenders, the researcher and other staff members were often approached by distressed family members or appointed care givers for advice or help. Anecdotal discussions with the family members then highlighted feelings of neglect and exclusion of the treatment and rehabilitation programmes. Arguments and either quiet or public emotional outbursts seemed to affect the mental health care user (MHCU) as well as the family member, which delayed the patient's recovery and progress. Forensic patients need physical and emotional support from their family members to help them cope in the hospital.

The family constitutes an important support system in the continuing care of the mentally ill persons, but the physical and emotional strain experienced by family caregivers cannot be ignored (Swaroop et al 2013). Some of the uncertainties the visiting families experienced were emotional and supportive, but also

financial, legal and the future fate of the criminal offender. The staff members working in the ward were not always available or knowledgeable in supporting the families, while most of their time was taken up with the patients.

Family members often shoulder the greatest responsibilities and burden of caring for their mentally ill relatives which are described as ranging from frustrations, depression, fear, sadness, anger, guilt, loss, stigma and rejection. The objective of the research then was to explore how families of male forensic patients experience being a care giver, but also being involved in the forensic mental health system, and what their needs are when visiting or living with a mentally ill family member.

1.5 THE PURPOSE OF THE RESEARCH

The purpose of the study was to explore and describe the experiences and needs of family members of the male forensic patients in closed units of a specialist hospital. The research purpose is the major intent of the inquiry and the population being studied and is a concise, clear statement of the specific goal of the study which is generated from the problem (Creswell, 2007:103; Burns & Grove, 2011:148).

1.6 CONTRIBUTION OF THE STUDY

The study is aimed at contributing towards the body of knowledge in forensic psychiatric nursing with regard professional development and in-service training phenomenon in order to reduce the family caregiver burden and to assist the family members or significant others to cope.

1.7 DISSEMINATION OF FINDINGS

The findings and recommendations will be disseminated through articles to peer reviewed journals and presentations at seminars.

1.8 THE RESEARCH QUESTIONS

The following research questions were asked:

- What are the experiences of family members of forensic patients?
- What are the needs of the family members of forensic patients?

1.9 THE OBJECTIVE OF THE STUDY

The objective of the study was to explore and describe the experiences and needs of family members/significant others of male forensic mental healthcare users in a specialist psychiatric hospital, and to recommend training and support for the Psychiatric nurses, families and forensic mental healthcare users.

1.10 ASSUMPTIONS OF THE STUDY

Assumptions are statements that are taken for granted or assumed to be true without any scientific proof or verification (Burns & Grove, 2011). Assumptions are principles that are accepted as true based on logic or custom (Polit & Beck, 2012: 720). In this study it is assumed that understanding the experiences and needs of families of male forensic patients would contribute towards the provision of knowledge and skills for psychiatric nurses working in these forensic units to enable them to offer the necessary support and information to the patients' families.

According to Creswell (2007:17), the philosophical assumptions in phenomenology include the epistemological, ontological, rhetorical and methodological assumptions.

The epistemology is described by Botma, Greef, Mulaudzi & Wright, (2010:40) as the way in which the researcher understands how people behave and why they behave in that way. It is the science of knowing and how knowledge is constructed. It questions and provides an answer on how we understand and know issues and what the researcher's relationship with participants is (Polit & Beck 2012:11) .The epistemological assumption relates to the relationship between the researcher and that which is being researched (Creswell, 2007:17).

The ontological assumption relates to the nature of reality and its characteristics (Creswell, 2007:17). When researchers conduct qualitative research, they embrace the idea of multiple realities. In this study, the researcher reported on the multiple realities, which were in the form of multiple quotes or statements and different perspectives of the participants on their experiences and needs of families of forensic patients.

The axiological assumption refers to the fact that the study is value laden and that biases are present (Creswell, 2007:17). The researcher applied the axiological assumption by recognising the value-laden nature of the study and by attempting to minimise biases in the study, as evidenced by the measures taken to ensure the credibility.

The rhetorical assumption determines the language of the study (Creswell, 2007:17). The qualitative and language terms were used and personal engagement with the participants ensured.

The methodological assumption determines the research process (Creswell, 2007:17). Methodology is the method that is practically followed when a researcher wants to study and understand something (Botma et al. 2010:40). In this study the researcher used qualitative research technique to best describe the experiences and needs of families of male forensic patients in closed units of a specialist hospital.

1.11 POPULATION AND SAMPLE

Population is the “process of selecting a portion of the population to represent the entire population so that inference about the population can be made” (Polit & Beck, 2008:33). The target population in this study refers to family members of male forensic patients in closed units of a specialist psychiatric hospital. The targeted population were family members, relatives who had known mental health care user for at least a year before or during the incarceration in a specialist psychiatric hospital.

The concept of purposive sampling is used in qualitative research. This means that the inquirer selects individuals and sites for study because they can purposefully inform and give understanding of the research problem and central phenomenon of the study (Creswell, 2007:127). Purposive sampling involves the researcher’s intentional choice of individuals or groups of people to participate in the study (Creswell, 2007:127).

According to Polit and Beck (2008:339), researchers specify the characteristics that delimit the study population by implementing the inclusion and exclusion criteria when selecting participants.

1.11.1 Inclusion and exclusion criteria

According to Polit and Beck (2008:338) the inclusion criteria are specific characteristics that participants should possess in order to be part of the target population. Participants were purposely selected according to the set sampling criteria, these were: A family member of a forensic mental healthcare user who was 18 years of age and above, agreeing to be interviewed and willing to give consent. A family whose male forensic MHCU relative was detained in closed units of the specialist psychiatric hospital. The participants were able to speak Basic English and were legally able to sign consent.

Exclusion criteria were used to exclude participants with specific characteristics that are not relevant to the study (Polit & Beck, 2008:338). Family members of male forensic patients in open wards and those who had less than a year knowing MHCU were excluded from the study, as well as those who were unable to reflect upon and relate in English their experiences, opinions and needs.

1.12 RESEARCH METHOD

A research method is the technique researchers use to structure a study and to gather and analyse information relevant to the research question (Polit & Beck, 2012:12). Furthermore research methods refer to data gathering, data analysis and ensuring rigour, Botma, Greef, Mulaudzi & Wright (2010:198). The research design and method will be discussed in detail in chapter 3.

1.13 THE PURPOSE OF THE RESEARCH

The purpose of the study is to explore and describe the experiences and needs of families/significant others of the male forensic patients in closed units of a specialist hospital. The research purpose is described by (Creswell, 2007:103) as the major intent of the inquiry and the population being studied. It is a concise, clear statement of the specific goal of the study which is generated from the problem (Burns & Grove, 2011:148).

1.14 DATA ANALYSIS

According to Creswell (2007: 148), data analysis in qualitative research consists of the preparation and organization of data for analysis, then reducing it into themes and sub-themes through the process of coding and condensing the codes and finally presenting the data in narrative format. The interviews will be conducted in English before being transcribed verbatim. The recorded, semi-structured interviews will be analysed and transcribed. The audiotape recording will be transcribed verbatim and then analysed using Tesch's open coding method (Creswell, 2009:117)

1.15 CONCLUSION

Chapter 1 provides an introduction to the study. The background, problem statement, the purpose, the design and the methodology of the study were outlined. The philosophical assumptions were discussed to indicate their relevance in the study.

In Chapter 2, the literature will be reviewed and discussed in greater detail.

1.16 OUTLINE OF THE STUDY

CHAPTER 1: Overview of the study and background.

CHAPTER 2: Literature review

CHAPTER 3: Research design and Methods

CHAPTER 4: Presentation of Results

CHAPTER 5: Discussion of the results, Recommendations & Conclusion

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

In chapter 1, an introduction and the background to the study were presented. A literature review, which is an organised, written presentation of what has been published about the topic by scholars, will be described. The purpose of the review is to convey to the reader what is currently known regarding the topic of interest (Burns and Grove, 2005:93). These authors further explain the literature review as a systematic and explicit approach to the identification, retrieval and bibliographical management of independent studies for the purpose of locating information on a topic, synthesizing conclusions, and identifying areas for future studies and developing guidelines for clinical practice.

Polit and Beck (2008:757) refer to the literature review as a critical summary of existing knowledge on a topic of interest, often prepared for the research problem to be contextualised. The following section will discuss the issues of mental illness and violence, the correlation between violence and mental disorder, the schizophrenia and crime, the theoretical perspectives on the correlations between crime and violence among persons with mental disorder, in order to provide the reader will an overview of the topic under discussion.

2.2 MENTAL ILLNESS AND VIOLENCE

Each year in South Africa hundreds of forensic patients with severe mental illness are admitted in specialist hospitals for treatment, care and rehabilitation. In a study by Calitz et al, (2006) in the Free State Province of South Africa, the following findings were reported:

- The majority of the offenders were males (94, 6%)
- They were single (66%)
- Their average age was 30
- The unemployment rate among them was 60%
- Main offences were: Theft (28%), murder (19%), assault (18%) and rape (16%)

- Schizophrenia was the most common disorder diagnosed (23%).

Forensic patients are mentally ill persons who are declared by courts to lack the capacity to understand court proceedings or are deemed to have been mentally ill when they committed the crime, Mental Health Act (Act No 17 of 2002). Forensic psychiatric hospitals play an important role in admitting forensic patients for psychiatric assessments and for providing treatment and rehabilitation. The patients are grouped according to their specific needs, problems or possible solutions. Firstly, there are those who are referred to designated forensic psychiatric hospitals for observations in terms of the Criminal Procedure Act, (Act no 51 of 1977).

Secondly, there are those that are admitted under the Mental Health Care Act (No 17 of 2002) to specialised forensic hospitals as state patients. And thirdly mentally ill prisoners admitted in terms of Mental Health Care Act because they are diagnosed as mentally ill whilst serving a prison sentence.

Forensic psychiatric hospitals are often geographically situated in the outskirts of the cities and in rural areas, making them inaccessible and unaffordable by family members wishing to visit their forensic mental healthcare users. There are currently ten psychiatric hospitals in South Africa that are used for both psychiatric observations and for detaining state patients and some mentally ill prisoners (South African Society of Psychiatrists and State Employees Special Interest Group (2012: 21). These facilities are often full thus increasing the long waiting list for persons requiring admission. This subsequently puts pressure on the forensic mental health system which often has to consider following options:

Sending state patients back to their families earlier than expected, which is often the context where the crime occurred, transferring them to “step down” facilities which are limited and at times far away from the families or sending them to long term chronic rehabilitation and treatment centres.

The longer the forensic mental healthcare user stays in the specialist hospital, the greater the impact of caregiver burden on their families. According to the World Health Organization’s “Assessment Instrument for Mental Health System” (WHO-AIMS (2007), the inpatient statistics for three South African Provinces

(Free State, KwaZulu-Natal and North West) reveal that 9% of users are incarcerated for less than one year, 25% of users spend 1-4 years in the facilities, 62% of users spend 5-10 years and 3% of users spend more than 10 years in forensic inpatient units. The majority of the patients admitted to these institutions suffer from some form of mental disorder. In the following section, theoretical perspectives on the correlations between crime and violence among mentally disordered persons will be briefly discussed.

2.3 SCHIZOPHRENIA AND CRIME

Schizophrenia is the most common mental disorder among forensic patients. Studies have shown that people with a diagnosis of schizophrenia are more likely to commit a criminal offence because of their vulnerability and the possibility of their being easily influenced. Their vulnerabilities could be exacerbated by a poor socioeconomic background, poverty, substance abuse and unemployment. Schizophrenia is often linked to criminal behaviours (Beech & Davies, 2012). However, Lay (2015) argues that most mentally ill people never commit violent crimes and schizophrenia is not sufficient cause for violence. The author asserts that several dispositional, historical and contextual factors which are well known to increase the risk of violence; family history of severe mental illness and violence and long-standing aggressive behaviour and repeated violent assault in the past, deserve an attention. It is therefore advised that any criminal activity involving mentally ill persons should be evaluated way beyond the mere presentation of psychotic symptoms, but consideration of the patient's historical and current life situations should be made to prevent future violent incidents.

Nevertheless, an increased number of studies have showed that the majority of forensic psychiatric patients are regarded as having a diagnosis of schizophrenia. The varying degree of caregiver burden of the families of the forensic patients is clearly linked with type of mental disorder that the forensic mental healthcare user is diagnosed with. Studies show that schizophrenia is the most common psychiatric disorder among forensic mental healthcare users. Many of the forensic mental healthcare users have enduring mental health disorders and they were known to their families and mental health system. Most

of forensic mental healthcare users have history of repeated multiple admissions to hospitals prior to committing their index offence.

Schizophrenia is a severe form of mental disorder in which the mentally ill person's reality testing becomes impaired and his perception of self, environment or the world is distorted, resulting in the creation of new reality. The impairment is said to be severe enough to cause hallucinations, false sensory perceptions in the absence of the external stimuli. The perceptual disturbances affect all different senses of the individual. The person may experience visual hallucinations in which he sees things that other people do not see. Auditory hallucinations are very common in schizophrenia in which a person hears voices or sounds that are not existent (Kneisel & Trigobbof 2009).

The mentally ill person can be commanded by these voices to attack other people whom he perceives to be a danger to himself. In some instances family members become victim of the mental healthcare user's violent behaviour, owing to his disordered thinking. In tactile hallucinations mentally persons may feel as if things are crawling up his skin. Perceptual disturbances such as tactile, olfactory (smelling), gustatory (taste) can be associated with tumours, infections or seizure disorders, therefore, their presence may require further investigations to exclude organic causes. To diagnose a person as having schizophrenia, the signs and symptoms should have persisted over a prolonged period of time (Kneisel & Trigobbof 2009:371). The criterion A symptoms must have been present for at least a month. The criterion A symptoms include: Hallucinations, delusions (false beliefs which are not consistent with the person's background, social status or education which a person continues to hold despite disconfirming evidence), disorganised behaviour (extreme body rigidity or flaccidity) and impaired affect (limited or absence of physical or verbal response). The negative symptoms of schizophrenia affect the person's mood and motivation. History of mental illness, the educational background, the cultural and sub-cultural membership of a person should be considered in the diagnosis of schizophrenia. Schizophrenia is a debilitating mental illness that can interfere with someone's ability to perform daily tasks and activities. Patients can be confused, withdrawn and may experience memory loss as well. The chronic and debilitating nature of schizophrenia means that the family members have to endure a lifelong

experience of care giver burden associated with care, treatment and supervision of the mental healthcare user.

Schizophrenia, according to studies, remains the most common mental disorder among forensic patients with (42%), followed by substance disorder at (33%) and mental retardation at (19%). The use of substances, like alcohol and drugs, are considered greater in people with psychotic disorder than in general population. Substance abuse is associated with greater risk of violent behaviour and non-compliance with medications and strong evidence of an increased risk of violence among forensic patients was found among those with the dual diagnosis of schizophrenia and substance abuse (Richards, Doyle & Cook, 2009).

In the case of mental illness as a defence against murder in a South African judicial system, it was proven that (63%) of those who lacked criminal responsibility were diagnosed as suffering from schizophrenia and (12,5%) were diagnosed as suffering from psychotic disorder not otherwise specified (Joubert & Van Staden, 2006).

In England schizophrenia was found to be the most prominent disorder commonly associated with violent crime, followed by learning disability (35%), personality disorders at (12%) and mood disorders at (8%) (Calitz, Van Rensburg, Fourier, Liebenberg & Van den Berg 2006).

2.4 CO-MORBID MENTAL ILLNESSES AND VIOLENCE

In a Canadian study it was discovered that the diagnoses of schizophrenia and other psychotic disorders do not significantly predict violence and criminal behaviour, but conditions such as personality disorder, anti-social personality traits, and psychopathic disorder, neuro-cognitive defects and substance abuse do contribute largely to crime and violent behaviour. It is believed that these factors are compounded by negative environmental factors and a poor social support system. The same author further attributed the link between mental illness and crime to other factors, such as personality difficulties (MacPhael & Verdune-Jones 2013).

Mentally disordered persons with co-morbid substance abuse are at increasing risk of committing violent acts. Substance abuse is frequently co-morbid with

variety of mental illnesses and levels of co-morbidity are reportedly elevated in mentally ill offenders (Matcheswalla & De Sousa, 2015).

The study conducted by Motojesi & Rataemane (2004) at a specialist Hospital in Gauteng province indicated that 9.2% of patients admitted over the period of two years for observations were intellectually disabled.

2.5 FAMILIES OF FORENSIC PATIENTS

Mental illness may be characterised by impairment in mental functioning, distorted thought processes, confusion, impaired memory and poor cognitive functioning. The person's ability to test reality is impaired to the extent of affecting his occupational, interpersonal and social functioning (Kneisel & Trigobbof 2009:371). The person's ability to fulfil his role obligations in the community is markedly impaired. Families sometimes experience stress of having to cope with mental health care user's disruptive behaviour, changes in household routines, strained social relations within the family, loss of social support, diminished opportunities for leisure and deteriorating finances (Navidian & Bahari, 2008)

The comorbid conditions such as substance abuse and mental disorder could easily lead to psychotic relapse due to non-adherence to treatment, resulting in disruptive behaviour by mental healthcare user and further straining of the relationship among siblings. The poor social support in the family can lead to disorganisation, substance abuse and conflictual relationship and increased caregiver burden on the primary family provider. The increased stress levels on the family caregiver could impact negatively on his/her health in general.

Studies for example by (Mueser & Drake, 2002), argued that people with a severe mental illness require prolonged psychosocial and psychopharmacological interventions in the hospital (cited in Richards et al, 2008). Prolonged hospitalization can put a strain on family resources which could result in stress and mental instability, and thus increasing their caregiver burden. Families of the forensic mental healthcare users would continue to incur huge financial costs related to travel and transport expenses. The prolonged

hospitalization would increase the strain on the family caregiver's relationship with other siblings, causing rejections, anger, guilt and depression.

2.6 THE CORRELATION BETWEEN CRIME AND VIOLENCE AMONG PERSONS WITH MENTAL DISORDER

Research findings of the relationship between mental illness and violent crime have been equivocal and have generated many discrepancies.

Over the years extensive studies have been undertaken in an attempt to discover the possible correlation between violence and criminal behaviour among mentally disordered persons. According to Sirotych (2008) variables implicated in the relationship between violence and crime among psychiatric patients are many but not limited to: demographic, historical, clinical and contextual factors

A study conducted in Swedish communities discovered that the odds ratio of mentally ill patients committing a violent crime were as high as 5.8% compared to 3.8% from population case registers (Fazel & Grann, 2006). Similarly a higher percentage of violent and criminal behaviour was reported among inpatient and outpatient mental health services. Some studies have demonstrated inconclusive results when comparing patients with severe mental disorders and other psychiatric conditions, (Fulwiler, Grossman, Forbes and Ruthazer 1997 cited in Sirotych, 2008).

Various authors, from various studies, as cited in Sirotych, (2008), argued that people with schizophrenia had a higher risk of committing criminal offences. Others, however believed that a diagnosis of major depression and manic disorders rather predispose a person to crime and violence (Eronen et al, 1996; Solomon & Drane, 1999; Modestin & Wurmle, 2005).

Clinical factors also play a role. A study conducted in Swedish communities discovered that the odds ratio of mentally ill patients committing a violent crime were as high as 5.8% compared to 3.8% from population case registers (Fazel & Grann, 2006). Similarly a higher percentage of violent and criminal behaviour was reported among inpatient and outpatient mental health services. Some studies have demonstrated inconclusive results when comparing patients with

severe mental disorders and other psychiatric conditions, (Fulwiler, Grossman, Forbes and Ruthazer 1997 cited in Sirotych, 2008). Various authors, from various studies, as cited in Sirotych, (2008), argued that people with schizophrenia had a higher risk of committing criminal offences. Others, however believed that a diagnosis of major depression and manic disorders rather predispose a person to crime and violence (Eronen et al, 1996; Solomon & Drane, 1999; Modestin & Wurmle, 2005). In the cohort study conducted in New Zealand involving (93.2%) 207 males and 15 females (6.8%) of Maori population, it was established that 121 (54.5%) of patients had diagnosis of schizophrenia, 43 (19.3%) had bipolar disorder and 23 (10.3%) had schizoaffective disorder. The majority of the cohort (176 or 79%) had contact with mental health services in the year prior to the index offence and only 21(9.5%) having attended forensic services (Brand, Mellsop & Tapsell, 2015).

2.7 DEMOGRAPHIC VARIABLES OF FORENSIC PATIENTS

Demographic variables such as age, socio-economic circumstances and race may predict both crime and mental illness (Matcheswalla & De Sousa, 2015). But the same factors such as poverty, lack of social support, divorce, poor education, disorganised home environment, unemployment, exposure to severe trauma, child sexual abuse etc. that affect mentally healthy individuals tend to affect mentally disordered persons extensively. Mentally ill persons are said to be more prone to violence outburst if they receive inadequate treatment and have long-standing paranoid delusions, and thus, are likely to commit criminal offence when they experience certain symptoms like command hallucinations (Matcheswalla & De Sousa, 2015); in other words if they are told by the voices to commit a crime.

In the general population, males are known to be more likely to engage in violence and criminal behaviour but in psychiatric settings the role that sex plays in determining the degree of violence and crime is uncertain. Sirotych, (2008) found that through studies of samples of recently discharged or admitted patients, males were less likely than females to display violent and criminal behaviour. These studies further revealed that females with the diagnosis of schizophrenia and other psychotic disorders are two to four folds more likely to

commit a criminal offence than males. However, in the South African context, the majority (94, 6%) of the schizophrenic patients with violent and criminal tendencies were males, (Calitz et. al. 2006).

Teenagers were reported to be at the highest risk of committing violence and criminal acts and that criminal behaviour among males with no mental disorder decreases with age (Sirotych, 2008), while violent crime was found to be more common among African- Americans than Caucasians and was arguably due to previous exposure to violent and criminal acts (Sirotych, 2008).

Although some authors of studies argue that people with schizophrenia had a higher risk of committing criminal offences, others, however believed that a diagnosis of major depression and manic disorders rather predispose a person to crime and violence (Eronen et al, 1996; Solomon & Drane, 1999; Modestin & Wurmle, 2005). A study conducted in Swedish communities discovered that the odds ratio of mentally ill patients committing a violent crime were also high (Fazel & Grann, 2006), while violent and criminal behaviour was reported among inpatient and outpatient mental health services. Some studies have demonstrated inconclusive results when comparing patients with severe mental disorders and other psychiatric conditions (Fulwiler, Grossman, Forbes and Ruthazer 1997 cited in Sirotych, 2008). Various authors, from various studies, as cited in Sirotych, (2008), argued that those who committed violent crimes and offences belonged to various cultural groups and either presented with schizophrenia, bipolar disorder or schizoaffective disorder (Brand, Mellsop & Tapsell, 2015).

Contextual factors, for example environmental stressors could lead to conflicting situations that may cause mentally ill persons to behave violently. Eighteen per cent (18%) of the stressors in the lives of mentally disordered persons emanated from adverse living conditions, unemployment, financial dependence, poverty, bad neighbourhood which led to violent crime (Sirotych, 2008).

2.8 SUMMARY

To add to the complexity of the relationships with offenders, violent crime committed by mental healthcare users against friends, neighbours, family members could alienate the family primary caregiver from the much needed support and results in strained relationship. Forensic mental healthcare users who have committed crime against the family primary caregivers can result in prolonging their stay in the hospital. Families might be frightened of the forensic mental healthcare users and not willing to accept them back when they are released from the specialist psychiatric hospital. As the vast majority of the victims of schizophrenic offenders are found among closest relatives, and family members being the ones on whom most of the burden of care is experienced, efforts to address the risk of violence should increasingly focus on the victims who should receive all the necessary support and counselling from the mental health professionals (Lay, 2015).

2.9 CONCLUSION

The complex issues surrounding mental illness and forensic admissions to a psychiatric hospital have been highlighted in the literature; however, the day to day experiences of the family members of those people admitted because of crime seem to suffer too often in silence. It could be because of shame or anger, but they are still burdened with the responsibility of a person in need of care and support. Future research needs to focus on the comprehensive understanding of various mental disorders and their relationship with criminal behaviour and not just limiting the study to few variables. To bridge the gap between the scientific research and psychiatric practice, integration of current knowledge into mental health care should be facilitated with regard to early assessment and the provision of evidenced-based treatment to address complex problems of people with serious mental illness who display aggressive and violent behaviours (Lay, 2015).

In the next chapter, the research design and method that were used to explore the experiences of the families of forensic male patients will be explained in full. The chapter clarified the plan and the structure of the study by discussing the research methodology in detail. The research method is a technique that is used to organize and structure a study in a systematic way from the start to the end (Polit & Beck. 2012:556). The chapter also reflected on the description of the various research design methods, qualitative, descriptive, explorative and contextual study designs that were utilized to meet the purpose of the research.

CHAPTER 3: RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

In the previous chapter, literature pertaining to the topic was reviewed and discussed.

In this chapter, the research method and methodology will be described in detail. The research setting, population and sample, means of selecting the sample, method, and design were outlined. In addition, the means to ensure rigour in the study will be discussed. Ethical considerations will also be emphasised.

The research design outlined in this study is qualitative, descriptive, explorative and contextual in nature. The qualitative design was used in this study to explore and describe the experiences and needs of families of male forensic patients in a specialist psychiatric hospital in Gauteng Province. The population and sampling method was explored and measures to ensure trustworthiness and methods used for data collection and analysis examined.

3.2 RESEARCH DESIGN

Kumar (2011:94) defines a research design as a plan, structure and strategy of investigation so conceived as to obtain answers to research questions or problems. The recorded, semi-structured interviews will be analysed and transcribed using Tesch's descriptive method of open coding (cited in Creswell 2007; Tesch 1992:141). A qualitative, descriptive and explorative design was used to explore the experiences and needs of families and significant others of male forensic patients in a specialist psychiatric hospital in Gauteng Province. The research design is the blue print of a study to ensure maximum control over factors that could interfere with the outcome of the study (Burns & Grove 2011:49).

3.2.1 Qualitative design

Qualitative research is used where little is known about the topic. In this study, little is known about how the relatives of patients who are incarcerated in a forensic unit experience the situation or what they perceive their needs to be. In qualitative research, the focus is not on the quantity, but on the quality of

information obtained from the people or situation. A qualitative research is a systematic, subjective approach used to describe lived experiences and to give them a meaning. It is also the way to gain insight through discovering meaning and exploring the depth, richness and complexity of the phenomenon (Burns & Grove, 2011:20). Qualitative research focuses on the quality of human experiences and actions. In qualitative research, a researcher often approaches reality from a constructivist position, which allows for multiple meanings of individuals' experiences (Maree, 2007:257). According to Uys and Basson (2005:50), the term qualitative indicates that these approaches concentrate on the qualities of human experiences and actions. Qualitative research explores attitudes, behaviour and experiences, and attempts to obtain an in-depth understanding from participants by conducting interviews Dawson, (2006:14-50).

(Creswell, 2007:240) describes qualitative research as an “inquiry process of understanding based on distinct methodological tradition of inquiry that explores social or human problems”. Qualitative research empowers the researcher to assist the participants to express and share their experiences of the phenomenon (Creswell, 2007:40). It allows rich narrative descriptions and classifications of themes and processes in order to understand the participants' experiences of the phenomenon (Polit & Beck, 2008:19).

Qualitative research should give a holistic account of the issues being studied by reporting the multiple perspectives and identifying many factors involved in a situation in order to map out a bigger picture (Creswell, 2007:39).

Inductive reasoning was applied by the researcher in reporting the phenomenon of interest. This is the process of reasoning from particular observations and facts to generalization (Polit & Beck, 2012).

The researcher chose the qualitative design in order to attempt to fully understand the holistic picture of the experiences and needs of family members of male forensic patients at a specialist hospital. Qualitative research involves an “interpretive, naturalistic approach to the world”. It focuses on phenomena that occur in natural settings that are in the “real world”. It also involves studying these phenomena in their complexity to make sense of and to interpret the

phenomena in terms of the meanings that people bring to them (Leedy & Ormrod, 2005:133).

3.2.2 Descriptive design

Qualitative research in this study is used to provide a more intense description of the experiences and needs of families of forensic patients. with the aim to describe what people feel, think and perceive after seeing and remembering their experiences (Polit & Beck 2008:228) A descriptive research design is structured in a way that provides a specific explanation of the characteristics, nature and intensity of a phenomenon (Polit & Beck, 2008:278). The phenomenon was described as experienced through all senses including “hearing, seeing, feeling, remembering, deciding, evaluating, acting and so forth” (Polit & Beck, 2008:228).

3.2.3 Explorative design

Explorative studies emphasise gaining ideas and insight about something in order to develop a better understanding of it. They are also used to increase the researcher’s familiarity with a problem which is relatively unknown. The topic under study has not been studied before in the specific context. Explorative research designs investigate the full nature of the phenomenon, the manner in which it is manifested and other factors related to it (Polit & Beck. 2008:20). The authors further elaborate that explorative qualitative research is designed to shed light on various ways in which a phenomenon is manifested and on underlying processes. The researcher explored the experiences and needs of family members/significant others of male forensic patients through conducting in-depth interviews and extensive literature reviews.

3.2.4 Contextual design

The study was conducted in the specialist hospital’s closed male forensic units. According to Creswell (2007: 40), contextual qualitative research is conducted when the researcher attempts to understand the context in which the participants address the problem. In this study, the data collected was only valid within the specific context. A contextual design selects cases within specific groups to accurately describe characteristics of the group context (Terry, 2011:163). Qualitative studies are always contextual, as the data is only valid in a specific

context. A contextual design is one in which the phenomenon under investigation is studied in terms of its intrinsic and immediate contextual significance (Klopper, 2008:68-69). In addition Jooste (2009:460) defines a contextual design as study results that are valid only for the situation in which the study was done. The research results and conclusions are only guaranteed under the circumstances that existed when the research study was conducted. In this study the experiences and needs of families of male forensic patients were at a specific location, namely: Specialist hospital in Gauteng Province.

3.2.5 Recruitment of participants

Recruitment is a systematic process where dates and times for meetings and venues are set before making contacts with participants (De Vos et al., 2009:540). Recruitment focuses on accessing individuals who are deemed to have a good knowledge about the study domain (Munhall, 2012: 235). The researcher was granted permission by the public health institution in Gauteng and obtained ethical approval from the University Human Research Ethics Committee of the University of the Witwatersrand and permission from the Faculty of Health Sciences' Post Graduate Committee before conducting the study. The wards' operational managers were approached to give permission to access the visitors' book. The prospective candidates were randomly selected and individually contacted telephonically at home. The phone numbers were randomly selected from the visitors' books in closed units of the of the specialist hospital. A meeting was arranged with each prospective participant when she/he came to visit a forensic mental health care user in order to meet for the first time and to hand over information leaflets and to clarify uncertainties before signing the consent forms. Majority of the participants (n=4) agreed to be interviewed immediately following debriefing and only (n=2) requested more time to go through the information leaflets and agreed to be interviewed during their next visit.

The potential participants were briefed about the nature of the research study and its objectives. The Information letters were written to inform potential participants about all details of the study. The venue, date and time of the interviews were confirmed in writing. Participants signed a consent form to

indicate their willingness to participate in the study and acknowledged that that they might withdraw their participation at any time without penalty. A separate consent to have the conversation audio-taped was given. The measures to ensure confidentiality of participants' information were explained. Code numbers were used instead of names to protect participants' confidentiality.

3.3 POPULATION AND SAMPLE

3.3.1 Population

The population in the study were family members of male forensic patients in the closed units of a specialist psychiatric hospital who met the sample criteria for inclusion in the study. According to Polit and Beck (2012:59), a population refers to the entire set of individuals with similar characteristics. Polit & Beck (2008: 33) state that sampling is the process of selecting the portion of the population to represent the entire population so that inferences about the entire population can be made.

Qualitative studies would aim to ensure that an understanding of a specific person or group that could apply to similar persons or groups in similar contexts and situations. Sampling refers to the selection of a subsection of the population for the purpose of the study (Polit & Beck, 2012:59). The target population in the study were family members of male forensic patients. Purposive sampling was used in this research study. Population with known characteristics and were knowledgeable about the situation or the issue were selected. The researcher selected individuals and sites for the study because they could purposefully inform and give understanding of the research problem being studied, and intentionally chose individuals to participate in the study because the information required could be obtained from them (Creswell, 2007:127). The families of the male forensic patients in closed units of the specialist hospital were selected based on their experiences and needs while taking care of them.

3.3.2 Sample and sampling method

The researcher was required to specify population characteristics required in the study to determine who met the inclusion and exclusion criteria (Polit & Beck, 2008:339). Families of male forensic patients admitted to the locked units of specialist psychiatric hospital were selected. Four closed male units with the bed capacity of approximately 12 patients each were chosen. Family members were interviewed until data saturation was achieved. According to Devos, et al (2005) purposeful sampling represents the researcher's judgement to include participants who reflect the characteristics or who are able to share the experience of people who are related to, care for or visited family members who were incarcerated in terms of the Mental Health Act of 2002 (forensic psychiatric patients).

- **Inclusion and exclusion criteria**

The inclusion criteria were specific characteristics that participants should possess in order to be part of the target population (Polit & Beck, 2008:338). Participants were purposely selected according to the set sampling criteria, these were: A family member/significant other of a male forensic mental healthcare user who was 18 years of age and above, agreeing to be interviewed and willing to give consent. A family whose male forensic MHCU relative was detained in closed units of the specialist psychiatric hospital. The participants were able to speak Basic English and were legally able to sign consent.

Exclusion criteria were used to exclude participants with specific characteristics that were not relevant to the study (Polit & Beck, 2008:338). In this study, family members who were unable to reflect upon and relate their experiences and needs in English were excluded including family members of male forensic patients in the open wards.

3.3.3 The interview guide

Data were collected by means of in- depth qualitative interviews, respondents were asked semi-structured, open-ended questions in an informal conversational type format (Polit & Beck 2008). Semi-structured interviews follow a fairly open framework which allowed focused, conversational, two way communication. Each interview was conducted on one-on-one basis to allow the interviewer to have control over the process and to allow the participants' freedom to express their views and thoughts freely. Each interview lasted for approximately 30 to 45 minutes. The participants were asked to describe their experiences of the phenomenon, the central questions that were asked being: "What are your experiences of living, visiting, or caring for a forensic mental healthcare user?" and "What are your needs and how would you like to be supported?"

Table 3.1: Advantages and disadvantages of semi-structured interviews

Advantages	Disadvantages
Questions can be prepared ahead of time	Interviewing skills are prerequisite
It gives participants freedom to express their views in their own terms	Requires sufficient sample to be able to generalise back.
It can provide reliable qualitative comparable data	Time consuming and intensive
It encourages two way communication	Researcher must be able to ensure confidentiality
Confirms what is already known and provides opportunity for learning	Careful preparations required to avoid asking leading questions
Participants are provided with the platform to discuss sensitive issues	Skills analysis skills imperative to avoid misconstruing information

Adapted from (Cohen, 2006) Advantages and disadvantages of the semi-structured interviews.

Semi-structured interviews are conducted with a fairly open framework which allows focused, conversational, two-way communication. Not all questions are designed and phrased ahead of time. The majority of the questions are created during the interview, allowing both the interviewer and the person being interviewed the flexibility to go into details when needed. Conducting a good semi-structured interview requires a thoughtful planning which includes: identifying participants, deciding on the number of interviews and preparing the interviews. After having conducted the interview, a comprehensive analysis is needed.

3.4 PROCEDURE FOR DATA COLLECTION

Data collection is a plan for precise, systematic gathering of information relevant for the research purpose drawn up for the purpose of the gathering of information needed to address a research question (Polit & Beck 2008:60). For the purposes of the study, data were collected by means of in-depth interviews, observations and field notes (Polit & Beck 2008: 394). Observation notes were recorded and used as objective description of events and conversations and behaviours during the conversation which included verbal communication cues such as pitch, tone and fluency of the speech and the non- verbal cues like body postures, facial expressions, eye contact and physical gestures.

3.4.1 In-depth interview

An in-depth interviewing is a face to face encounter between the researcher and the informants that is directed towards understanding their perspectives on their lives and the situation as expressed in their own words (Kumar, 2011:160) Data were collected by means of in- depth qualitative interviews, asking respondents semi-structured, open-ended questions in an informal conversational type format. Semi-structured interviews follow a fairly open framework which allows focused, conversational, two way communication. Each interview was conducted on one-on-one basis to allow the interviewer to have control over the process encourage the respondents' freedom to express their views and thoughts freely. Each interview lasted for approximately 30 to 45 minutes.

The participants were asked to describe their experiences of the phenomenon, the central questions that were asked being: "What are your experiences of living, visiting, or caring for forensic mental healthcare user?" and "what are your needs and how would you like to be supported?" The researcher used verbal and non-verbal communication skills such as posing open-ended questions, probing the interviewee's responses when necessary, reflecting on the content and the feeling conveyed by responses, exploring, paraphrasing, using silence to elicit information from the participants. Interviews were conducted until saturation was reached in that no new themes emerged.

3.4.2 Field notes

According to Polit & Beck (2008:304), field notes are notes taken by the researcher as unstructured observations in the field and interpretation of those observations. Field notes are written immediately after the interview as a record of the researcher's impression of what was said by the participants. This gives the researcher enough time to reflect on the information collected during the interview before moving on to the next interview. They also assist the researcher to synthesize and analyse the data (Polit & Beck 2008:404-405). Field notes are notations made to document observations that become part of data analysis (Streubert & Carpenter 2011: 42). Field notes were written during the interview. The researcher recorded additional notes immediately following each interview. Field notes are useful in the sense that they are much broader, more analytical and interpretive in nature and assisted the researcher in the synthesizing and analysing of data (Polit & Beck, 2008:404)

The researcher used the field notes to identify and interpret feelings, ideas, attitudes, impressions of the families of the forensic patients relating to their experiences of the phenomenon and to capture non-verbal behaviours. The researcher kept the field notes to be used as a backup if the audio recordings failed. The researcher's field notes comprised of: observational notes, theoretical notes and personal notes and are interspersed in the verbatim transcripts of the interviews to add depth and context to each interview.

- **Observational notes**

Observations enabled the researcher to gain an understanding and deeper insight into what was being observed and recorded, for example; Verbal and non-verbal behaviours such as hesitation, voice tone and pitch, signs of distress, anger or anxiety. An observation is a powerful systematic and selective way of watching and listening to the phenomenon as it happens while studying the behaviour and personal traits of an individual (Kumar, 2011:141).

- **Theoretical notes**

These are researcher's interpretation of what was been observed during the interview. Theoretical notes were used to document the researcher's thoughts of

what was going on and what's being said or shown by the participants while the researcher compared what was being said by various participants in an attempt to elicit common themes.

3.4.3 Personal notes

These are comments made about the researcher's own feelings elicited during the research process. They document the researcher's own reactions, reflections and experiences during and following the interview.

3.4.4 The use of a tape recorder

There are wide varieties of technical devices that can be used for recording behaviour and events to make data analysis at the later stage possible (Polit & Beck, 2008:317). Interviews were recorded using a tape recorder. Participants were able to express themselves freely as the procedure had been explained to them and all had agreed to the interviewing being recorded. Audiotapes were transcribed verbatim immediately following the interviews, the field notes inserted and the recording checked for accuracy against the recording. The information on the use of the tape recorder was explained in the consent form that the participants signed (Appendix A).

3.4.5 Communication skills used during interviews

- **Listening**

Good listening was a critical skill for in-depth interviewing and allowed the participants' ample opportunity to express their views uninterrupted (Polit & Beck, 2008:400).

- **Paraphrasing**

Paraphrasing involved re-stating someone's words clearly and concisely in a different form but retaining the same meaning.

The researcher validated and summarised statements in order to verify what respondents were saying during the interview (Burns & Grove, 2011:220).

- **Probing**

Probing techniques were used to elicit more and detailed information from the respondents about an issue under study when it's not volunteered (Polit & Beck, 2008:738).

3.5 ETHICAL CONSIDERATIONS

The following ethical principles were considered: beneficence, respect for human dignity, confidentiality and informed consent (Polit & Beck 2008:170–175).

3.5.1 Beneficence

The principle of beneficence encompasses a duty on researchers to minimise harm and maximize benefits (Polit & Beck 2008:170). Participants were given the opportunity to share their experiences of caring for mentally ill forensic relative. Measures were taken by the researcher to ensure that participants were not harmed in any way during the study. Harm and discomfort are classified as physical injury and fatigue, emotional harm as stress and fear; social harm as loss of support; and financial harm as loss of income, (Polit & Beck, 2008:170).

The researcher aimed to provide support to the participants experiencing emotional distress during the study. The right to protection from exploitation occurs when participants are placed in a disadvantaged position by the researcher, exposing them to a situation for which they were not prepared (Polit & Beck, 2008:171). The participants were informed of their rights to withdraw, should they desire to do so, without any prejudice.

3.5.2 Respect for human dignity

This includes the right to self-determination and full disclosure (Polit & Beck 2008:172). Prospective participants were informed that participation was voluntary, and that they had the right to decide whether to participate in the study or withdraw from it at any time without any prejudice. The confidentiality and anonymity of the patients and family members was ensured as code numbers were used and no names or identifying data were used on the transcribed notes. The raw data was locked away and was only available to the researcher and the supervisor.

- **The right to self-determination**

Humans should be treated as autonomous agents, capable of controlling their own activities and destinies (Polit & Beck, 2008:160). The right to self-determination is based on the ethical principle of respect for persons and it indicates that humans are capable of controlling their own destiny (Burns & Grove, 2011:110). The participants had the right to ask questions, to refuse to give information and to withdraw from the study at any time (Polit & Beck, 2013:84).

- **The right to full disclosure**

Full disclosure means that the researcher has fully described the nature of the study, the participants' right to refuse to participate, the researcher's responsibilities and the likely risks and benefits that would be incurred (Polit & Beck, 2008:160). The information was provided to participants before the study and a provision was made for subsequent disclosure. In this study the objectives and purpose of the study were communicated to the participants before the commencement of the study.

3.5.3 Confidentiality

Confidentiality is maintained by the researcher's management of private information shared by a participant and must not be disclosed to others without the authorization of the participant (Burns & Grove, 2011:117). In this study participants remained anonymous and the information was kept confidential. The researcher ensured that personal rights and privacy of participants were adequately protected, by refraining from including their names in the research report. Information from participants was not and shall not be made available to unauthorized people (Streubert & Carpenter, 2007:268).

3.5.4 Informed consent

Polit and Beck (2008:176) assert that informed consent should be based on adequate access to information regarding the study and awareness of the right to voluntary participation. Consent is the prospective participant's agreement to participate in a study which is reached after assimilation of essential information (Burns & Grove, 2011:123). In this study the researcher included the following in the information leaflet: explanation of the research activities, benefits of participating in the research study, provided assurance about confidentiality and anonymity, and their rights to ask the researcher questions and options to withdraw from the research study. The researcher then explained the contents of the information leaflet to all the participants (Burns & Grove 2011:125).

3.5.5 Justice

Burns and Grove (2011:107) state that the right to fair treatment is based on the ethical principle of justice, which holds that each participant should be treated fairly and receive what he or she is due or owed. The principle of justice means that participants should be treated fairly, Botma et al, (2010:19). The researcher ensured all the personal notes, the field notes and observational notes were locked away in a secured area accessible only by the researcher. The research protocol was adhered to when issuing the information leaflets with emphasis on the rights of the participants and measures to ensure confidentiality.

3.6 DATA ANALYSIS

Data was analysed using Tesch's method of qualitative data analysis (Tesch, 1992:117). Data analysis involve reducing the volume of raw information, sifting significance from trivia, identifying significant patterns and constructing a framework to communicate the essence of what the data reveal (De Vos et al. 2011: 252). Brink, Van der Walt and Van Rensburg, (2012:192), describe data analysis as the process of bringing order, structure and meaning to the mass of collected data. The data were collected using digital voice recorder. The interviews were conducted in English and later transcribed verbatim. The transcribed audio-recorded interviews and field notes were analysed using Tesch's method (1992) as cited by Creswell (2009:192). The transcribed audio - recorded interviews and field notes were analysed to search for words, phrases, themes and sub-themes that were central to the research topic. Following each interview, the researcher listened attentively to the content of each recorded voice to note any changes in the expression of the tone and emotions. The transcriptions were typed and read repeatedly to note similar recurring words and phrases which reflected representative experiences of families and significant others of male forensic patients. Data were analysed and systematically explored to generate meanings. A select few participants were asked to validate data for accuracy of transcription. The participants who gave more detailed information and those who provided different stories about their experiences were selected to review the transcriptions. Themes and sub-themes were generated from the coded data (family needs & recommendations). Analysed data were then subjected to peer review and discussion to reach agreement on major themes and recommendations. Colleagues, managers and professionals with masters' degrees in advanced psychiatric nursing were selected for peer review.

3.7 MEASURES TO ENSURE TRUSTWORTHINESS

Polit and Beck (2008:768) describe trustworthiness as the confidence the researcher has in the data assessed. To ensure the trustworthiness of data collection and interpretation, the framework as described by Lincoln and Guba (cited in Polit & Beck, 2008:539–540) was applied to enhance credibility, dependability, conformability and transferability.

3.7.1 Credibility

Credibility refers to confidence in the truth of and the researchers' interpretations of the data (Polit & Beck 2008:539). In this study, credibility was ensured through the researcher's prolonged engagement, peer debriefing, triangulation and member checking of the participants.

3.7.1.1 Prolonged engagement

In this research study participants were given ample opportunities prior to the interviews to ask questions in order to clarify issues of concern. Participants were also given time to ask questions during the interview and good relationship, trust and rapport were established in that manner. The reciprocal exchange of information between the researcher and the participants provided accurate information which benefited the research study.

3.7.1.2 Peer debriefing

The researcher discussed the research process and the findings with the supervisor, co-supervisor and researchers from other institutions who were experienced in qualitative methods. Polit and Beck (2008:548) describe debriefing discussion sessions with peers to review and explore various aspects of the inquiry as a way of making data trustworthy. Botma et al. (2010:232) define it as a discussion with peers not involved in the research.

3.7.1.3 Triangulation

Polit & Beck, (2008:768) define triangulation as the use of multiple data collection methods to address a research problem such as observation and structured interviews. In the study the multiple methods of data collection that the researcher used were semi-structured interviews, field notes, personal notes and observational notes.

3.7.1.4 Member checking

Member checking is a continuous confirmation of the accurateness of data and themes with the participants prior to drawing a conclusion about research findings (Polit & Beck, 2008:545). In this study the researcher discussed the data with the participants to verify its accuracy of the information obtained during the interview.

3.7.2 Dependability

Dependability refers to the stability of data over time and over conditions (Polit & Beck 2008:539).The researcher's supervisor and co-supervisors checked to determine whether the procedures followed in the study were acceptable attested to the veracity of the transcriptions and authenticity of the coded data.

3.7.3 Transferability

Transferability refers to the generalising the data and the extent to which findings from the data can be transferred to or have applicability in other similar settings or groups. In this study the researcher used purposive sampling and has provided a detailed description of the research setting and findings (Polit and Beck, 2008: 539).

3.8 CONCLUSION

Chapter 1 has provided an overview of the background and problem statement, the purpose of the study and the research design and method used to obtain the data. The objective of the study was to explore and describe experiences and needs of families of the male forensic patients in a specialist hospital in Gauteng. Chapter 2 dealt with the literature review.

The research setting, population, sample and instrumentation used to conduct the study and the protection of research participants were discussed in chapter 3. And in the chapter, the researcher described the actual process of data collection. The chapter on data analysis extensively explained how data were converted to information, thorough description of the sample and analysis of the narratives. Chapter 4 will deal with the presentation of the results were themes and sub-themes emerged.

CHAPTER 4: PRESENTATION OF THE RESULTS

4.1 INTRODUCTION

In chapter 3, a detailed description of the research design and method used were discussed. In this chapter, the experiences and needs of families of male forensic patients in a specialist hospital that were expressed during the interviews will be explored and reported on.

The narratives were obtained during the semi-structured interviews and were analysed by using Tesch's method of open coding (Creswel, 2007:158). The researcher's observational notes were also used to document verbal and non-verbal behaviour observed during interview.

4.1.1 Demographic profile of the participants

All the participants met the criteria set in chapter 3. Most participants were females and worked in various fields. The male participant was self-employed. He made living by selling vegetables in the township street. All participants were individually and privately approached to obtain their consent to participate in the study. Ethical principles were adhered to at all times during the study. All participants signed the consent form and gave permission to be interviewed and be audio taped (Appendix A). All participants were able to communicate in English.

Table 4.1: The Demographic profile of the participants

No.	Gender	Age	Marital Status	Race	Employment	Relationship with MHCU
1	Female	35	married	black	Full time	Sister
2	Female	48	single	black	Full time	Sister
3	Male	54	widowed	black	Self employed	Father
4	Female	60	married	white	pensioner	Mother
5	Female	58	single	black	casuals	Mother
6	Female	59	single	black	casual	Mother

All the interviews and observations were conducted in the hospital after obtaining permission from the chief executive officer of the specialist mental health institution. The times and the duration of the interviews, as suitable and convenient to the researcher and participants, were agreed to. All interviews were conducted during the day. The central questions asked to all participants were, “What are your experiences of living, visiting or caring for a forensic mental healthcare user?” and “what are your needs and how would you like to be supported?” The interviews were transcribed and analysed using Tesch’s method of open coding (1992) cited by Creswell (2009). The data analysis was supported by verbatim quotes from interviews.

4.2 THE INTERVIEW ENVIRONMENT

The research was conducted in a Gauteng psychiatric institution and families or significant others of the mental health care users admitted under Act (Act no. 17 of 2002) were interviewed. All Mental health care users were admitted as forensic patients in closed units of the specialist hospital. In the closed units where the interviews were conducted, rooms suitable for conducting interviews were provided.

4.3 OBSERVATION MADE DURING THE INTERVIEW PROCESS

Before the interview, each participant was briefed about the research objectives, benefits, potential hazards and the process of interviewing and the entire study, which included the ethical measures and confidentiality.

During the interview process, most participants appeared apprehensive in relating their experiences and challenges to others. Some participants mentioned that they had regrettably confided to close relatives as they felt that they did not want to be a burden to anybody. Some family members expressed sense of isolation from the community and other family members due to their loved ones forensic history and mental illness. Though most participants expressed their experiences freely, some required further probing questions to get clarity on their views. All participants expressed feelings of hopelessness and anger when asked to describe their experiences. Other participants blamed their poor parenting skills for their family member’s predicament. Some participants appeared anxious and agitated and seemed uneasy to be audio- taped though

its use and purpose were thoroughly explained to them. Non-verbal cues observed during interview process were tapping of feet on the floor, staring at ceilings, grimacing, hands wringing, and abrupt silence. Some participants were observed to be crying during the interviews while others seemed to have thought block.

4.4 PRESENTATION OF THE RESULTS

The results were presented according to themes, and sub-themes or categories. In this research study, six interviews were conducted until saturation of data was reached. As seen in table 4.4, the central themes identified during the interviews with the families of the male forensic mental healthcare users were under pinned by sense of “perceived failure” linked to perceived poor parental expectation/supervision and strained relationships with other family members. The coding was guided by Tesch’s method (1992) following the central research questions, “What are your experiences of living, visiting or caring for a forensic mental healthcare user?” and “what are your needs and how would you like to be supported?”

Table 4.4: Themes

THEMES	CATEGORIES	QUOTES
1. Perceived poor parental expectation	1.1 Poor supervision and lack of knowledge 1.2 .Perceived failure as a parent	<i>“He just had no idea about his medicine how he should take it; he needed somebody to constantly remind him to take his tablet” (p1). ” I just don’t think I did enough to ensure that he was well looked after when I was away” (p4)</i>
2. Strained relationship with others.	Strained relationship with others: 2.1 Forensic MHCU 2.2 siblings and relatives. 2.3 between siblings, relatives and a forensic MHCU	<i>“I am currently taking loads of medication because of his endless demands, he doesn’t feel any sorry for me, and I am like his slave...” (P2). “I am just coming here because of threats he makes when I don’t come to visit him (p3) “” Everybody at home is so scared</i>

		<p><i>of him including our neighbours, I am worried that he might get hurt by people at home due to his aggressive behaviour”(p1).</i></p> <p><i>“My other children and relatives don’t want to visit him; they believe I spoil him “(p1).</i></p>
3. Emotional impact of care-giving	3.1 feeling of hopelessness, helplessness and despair	<p><i>“It hurts seeing him in this state; it doesn’t look like he’ll be better than this “(p2).</i></p> <p><i>“I have no one to turn to, I feel like I am losing this battle” (p1).</i></p> <p><i>“I really don’t know what to do, I am exhausted, I have no energy left” (p3).</i></p> <p><i>“It feels like God has deserted me....sobbing.... (p1).</i></p>
4. Financial and employment impact of care-giving.	4.1 Costs: Transport Travel Employment Expenses(other)	<p><i>“ I am afraid that I may lose my job one day, I keep requesting leave days and taking sick days, at times I don’t get paid” P3).</i></p> <p><i>“I have to do several piece jobs (casuals) in order to provide for the entire family” (p2).</i></p> <p><i>“I can’t do anything for myself; I can’t even afford to visit other relatives living far away from us” (p6)</i></p>

Not only did the family members experience a sense of failure, but also increasing care-giver burden and needed a support. The emotional impact on their care-giver role led to a sense of hopelessness and helplessness which were exacerbated by the financial impact and effect on employment.

The themes and categories identified in the results section will be discussed below in the in the same order as they appeared.

4.4.1 Experiences of poor parental expectations

Most forensic mental health care users were known by family members to be suffering from some form of mental disorder and were receiving medication. Some participants mentioned that due to poor supervision at home of the mental healthcare user, his mental state deteriorated to an extent that he ended up committing a criminal offence.

4.4.1.1 Poor supervision and lack of knowledge

Participants believed that proper and continuous support structure at home could have ensured treatment adherence. They mentioned that mental healthcare users needed support to attend to their basic needs like cleanliness, cooking and eating, stress management and medication administration. Some family members expressed little knowledge about mental health care users' psychiatric disorders. The participants seemed to lack in-depth understanding of mental healthcare users' illness and their ability to function within the community. They had no idea of what educational information was given to mental healthcare users when discharged but were under the impression that their care and support to their mentally ill loved ones had been adequate. However, their lack of sufficient information and resources also proved to be an obstacle that rendered their caring role ill-prepared and less efficient (Shamsaei, Cheraghi & Esmaeilli 2015).

Forensic psychiatric services frequently receive patients who have offended after previously been on psychiatric treatment (Brand, Mellsop & Tapsell, 2015). Family members acknowledged that majority of the mental healthcare users were mentally ill before committing the criminal offence. Some mental healthcare users had history of multiple admissions to hospitals. Families reported that MHCUs defaulting of their treatment resulted in psychotic relapse. Participants hardly remembered being involved in the treatment programme of their loved ones during patients' previous hospital admissions. Some mental healthcare users were reportedly involved in numerous petty criminal offences prior to committing their index offence.

Participants lacked information about their mentally ill loved ones in relations to diagnosis, treatment and prognosis. Family members were dissatisfied with the

lack of support from the hospitals and primary health care services. They blamed themselves for failing to arrange somebody to supervise mental health care users while they were at work.

"I thought he was well prepared to take care of himself at home during his multiple admissions at the psychiatric hospital and at the local clinic where he gets his treatment" (p4).

"He just had no idea about his medicine how he should take it; he needed to be constantly reminded to take his tablet" (p1).

"I remember picking my son up after discharge but nobody gave any information about his condition, I was told a little bit about how he should take his medication".(p3).

"umm, he once told me that he used drugs to help ease the side effects of his medication and to deal with boredom, but I just shouted at him....." (p3).

Comorbid problems of substance abuse and personality disorders were also found to be common among forensic patients, which complicated treatment and rehabilitation. Poor supervision of MHCUs at home following discharge increased his vulnerabilities of being influenced by others to use substances. Participants mentioned that MHCUs used substances to deal with boredom and or to counteract the side effects of their medication. Substance abuse among mentally disordered persons can contribute towards aggressive and criminal behaviour which could result in strained relationship with families, siblings and friends.

4.4.1.2 Perceived failure as a parent or caregiver

Parents expressed self-blame for their perceived failure to execute their parental responsibilities. Family members are primary source of supporting mentally ill individuals. When a lone working family member cared for mentally ill relative, caregiver burden and stress level escalate. . When adverse life events seem to retard the child's progress, parents tend to blame themselves for child's failure. Family members blamed themselves for having mentally ill family members.

Some families scrutinise themselves for the way in which they nurtured their children, and questioned their parenting abilities. Mothers reported feeling

despised by the society for not producing kids that met the societal expectations. When a family member became institutionalised a caregiver attempted to do his/her the best to help in order to compensate for the perceived failure.

Caregivers or family members who attempt to balance their caregiving responsibilities with work, family and leisure activities, found it difficult to focus positively on caregiving and experience more negative reactions such as increased sense of burden. (Pusey-Murray & Miller 2013:114). The parents blamed themselves for not providing adequate care and supervision when relative with mental illness defaulted treatment and ended up with psychotic relapse.

Caregivers and family members mentioned how they struggled to fulfil multiple roles that were demanded of them, which resulted in an increased stress level associated with household, work and caregiving Pusey-Murray et al (2013:114).

"I don't have time to rest or to be with my other children" (P5).

"I don't get enough rest as I have to do several piece jobs to be able to provide for everyone at home". (P2)

Participants blamed themselves as parents and felt that they did not do enough to ensure their mentally ill relatives received the attention and care that they deserved from family members. Some participants expressed guilt feelings about their failure to do everything possible to ensure that their mentally relative was properly looked after.

" I just don't think I did enough to ensure that he was well looked after when I was away" (p4).

Most participants mentioned that there were other family members at home during the day but they were reluctant to help supervise the mental healthcare user.

4.4.2 Strained relationship with others

4.4.2.1 Strained relationship with forensic mental health care user

Failure to understand the forensic mental health care user's condition caused unnecessary strain on the caregiver's life. Families did not know how to assist mental healthcare user when he experienced medication side effects. A family member would give in to patient's demands to buy him groceries just to please him. Long distances travel by families to visit the mental healthcare user in hospitals caused physical, psychological and financial strain on a family caregiver. Some participants attributed their physical strain and having health problems to the demanding nature of the forensic patients. Others believed their stressful lives contributed to their poor state of health such as having high blood pressure, diabetic and headaches.

The chronic stress of caregiving was reported to have affected numerous dimensions of caregivers' health; including self-reported health symptoms, illnesses and medication use, Shamsaei, Cheraghi & Esmaeilli (2015). The same authors concluded that majority of the participants interviewed in their study used significantly more prescription medication than non-caregivers. Most participants in this research study mentioned their daily use of medication as their way to cope with their difficult experiences.

"I am currently taking loads of medication because of his endless demands, he doesn't feel any sorry for me, and I am like his slave..." (P2).

Participants admitted taking medications including anti-depressants to help them deal with what they described as "stressful situations". The participants mentioned that they felt exhausted from either use of medication or as a result of stress.

"I feel weak all the time; it seems as if the medication is not doing me any justice... (p4).

"I keep on changing to different medicine because I am miserable all the time, I take so many tablets each day, I don't even know their names" (p6).

Swaroop et al (2013:30) agreed that, hence caregiving can be an emotionally draining experience; caregivers often have high rates of depression when compared to general population. Some caregivers expressed a sense of hopelessness, despair and a wish to die to end their sufferings.

“I just become emotionally numb sometimes; mental and physical exhaustion is so unbearable, it’s better to be dead than alive, the stress is too much, he demands things all the time” (p2).

“I am not enjoying this life at all, my body is about to give up” (p1).

“The pain i feel all the time cannot just go away, something has got to give, my life is a big mess, and don’t I deserve peace at least? I am emotionally bruised and nobody cares” (p3).

My depression medication is my only lifeline, although it makes me sleepy at times, but I can’t live without it” (p4)

Participants expressed their emotional agony in many different ways. Some wished they were dead. All participants felt hopeless and helpless and believed that they were on their own and nobody cared about them. Participants reported that they were receiving medication for depression. Some participants reported that they visited the forensic MHCU in the hospital because of the constant threats that he made towards them if they took too long to visit.

Non-compliance with medication or poor response to medication could cause the patient to be physically or verbally aggressive towards a caregiver, and thus straining the relationship even further. The family members or caregiver were reported by Pusey-Murray & Miller (2013:114) to be concerned about the threats from their severely mentally ill relative and recommended that families be included in the decision making and discharge planning. When mental healthcare users defaulted their treatment, the family members felt the consequences of their aggressive behaviour. Some patients stopped taking their medication when they started feeling better and subsequently suffered psychotic relapse.

"I am concerned about his aggressive behaviour; he threatened me several times before when I tried to give him his medication". I don't know if I will cope when he is discharged" (p6).

"I am just coming here because of threats he makes when I don't come" (p3)

"When he does not take his medication properly, he relapses and becomes aggressive towards all of us at home" (p2).

"Everybody at home is so scared of him including our neighbours, I am worried that he might get hurt by people at home due to his aggressive behaviour"(p1).

"He has no idea how helpful his medication is, he thinks that when he's well he can just stop it" (p1).

Physical aggression was a major concern from the majority of the participants. They felt threatened by prospects of the forensic patients being discharged home one day. Non-compliance due to poor insight by the patient was mentioned by participants as the main cause of aggressive behaviour. Participants believed that some of the patients were easily influenced by peers to stop taking their medication. They were concerned about lack of adequate continuous supervision at home as patients would be on their own during the day. The expression of fear by most participants was compounded by lack of supportive structure in the community and from the hospital.

The participants felt alienated and all alone and unsupported by police when the patient became aggressive at home. Some participants mentioned that they had to visit the patient in the hospital because they care about them even though they felt threatened. Other participants said that their support for the patients was done out of fear. They believed that patients would attack them out of vengeance when discharged if they did not visit them in the hospital.

Family member or caregivers also mentioned that because of forensic mental health care user demands, other family members refused to visit him in the hospital, thus increasing the burden of care on one person. Family caregivers often complain about lack of time to attend to their own needs like social relations

and recreational activities, and thus alienating themselves from much needed friends and family support (Ae-Ngibise et al (2015)).

4.4.3 Strained relationship with other siblings and relatives

When a family member is detained in a hospital indefinitely due to mental illness, other siblings are required to offer a helping hand. But, a mentally ill care user who is perceived by siblings to consume all valuable time and family resources may cause resentments to develop against the main caregiver resulting in disharmonious relationship. The main caregiver may devote too much time focusing in the forensic patient at the expense of other family members and thus alienating herself/himself from the much needed support of relatives and other family members Ae-Ngibise et al (2015).

“My other children and relatives don’t want to visit him; they believe I spoilt him” (p1).

“I have a big dilemma here, he is my child too, I cannot just abandon him” (p4).

“I feel like though, that at times he’s being manipulative and just want, want and want with no regard for me and others”P4).

The relationship with other family members becomes strained due to their lack of support. The family primary caregiver who does not get any form of support from other family members is likely to experience physical and emotional stress. The family members of the primary caregivers were reluctant to visit the forensic mental healthcare user at the specialist hospital. The lack of support from family members often lead to conflict between MHCU and healthcare professionals resulting in to poor adherence to treatment . Non- adherence to treatment has strongly being associated with poor family support.

“My other children refuse to visit their brother in the hospital, they blame me for all his behaviour, I feel like I am on my own here.....nobody cares” (P4).

Caregivers who don’t get assistance from other family members may try to do more than they are capable of doing, resulting in physical or financial burnout (Settineri, Rizzo, Liotta & Mento, 2014). Caregivers who have “burnout” may

experience fatigue, anxiety and depression. Regardless of an uneasy relationship with other siblings, some caregivers often have feelings of guilt if they spent less time with the mentally ill persons. More negative impact of caregiving experiences include among others: constant disputes or disagreements among family members, decreased family outings and activities due to economic difficulties, decline in work performances and alcohol abuse by the caregiver.

4.4.3.1 Strained relationship between siblings, relatives and forensic mental healthcare user

Family members and relatives of the forensic mental healthcare user who lack understanding of his mental conditions may lead to poor relationship with him. The mental healthcare user might become impulsive and display threatening behaviour at times. There are times when the patient has impaired communication due to mental illness or side effects of his psychiatric medications. The lack of knowledge by family members and relative about psychiatric disorders may deter them from visiting the patient in the hospital.

Some relatives of the participants accused the mentally ill individuals of being too demanding and manipulative. Caregivers and their families need support in the form of education so that mental illness is not misconstrued and stigmatised, Aengibise et al (2015). When family members and relatives are provided with the information about the patient's mental condition in relations to his diagnosis, accompanying symptoms and behaviour as well as strategies that they can use to manage him, feelings of mastery increase and feelings of blame towards family member and personal feelings of guilt decrease, Shamsaei et al (2015).

"I have been accused by my other children of spoiling my child for buying him things and visiting him regularly" (p3).

"My older daughter is scared of him, she believes he is too dangerous and makes threats all the times, she thinks he's ungrateful for the little things that they buy him" (P5).

"He is accused of demanding too much and all the attention given to him" (p2).

Caregivers experience emotional instability when mentally ill patient display aggressive behaviour towards siblings and friends, Ae-Ngibise et al (2015). A Lack of skilled staff members to help clarify the patient's behaviour and to receive feedback about visit and to encourage further interaction with the patient remains to be a serious concern. Some psychotropic drugs may cause the patient to display signs and symptoms that mimic increased psychotic agitation and restlessness that could easily be mistaken for aggressive behaviour. The majority of the participants did not know the diagnosis of their mentally relatives and the treatment they were placed on.

4.5 EMOTIONAL IMPACT OF CARE-GIVING

Caring for a person with chronic mental illness can be more stressful than caring for people with a physical disability, Shamsaei, Cheraghi & Esmaeilli (2015). Most participants associated their caregiving experiences with their increased stress levels and the deteriorating health. The unchangeable and unpredictable nature of the patients' behaviour was reported by most participants who felt stressed, sad and worried. The families were concerned and worried about the future and prognosis of the mentally ill relative.

Most caregivers of mentally ill individuals reported emotional distress as they found themselves often thinking a lot about them and the embarrassment that sometimes accompanied it, Ae-Ngibise et al (2015). Caring for the forensic mentally patient can be quite challenging leading to feelings of hopelessness and despair.

4.5.1 Feelings of hopelessness and helplessness and despair

Caregiving can be an emotionally draining experience which may result into depression of the primary caregiver. The emotional impact of caregiving of psychiatric disorders on families can vary from fear, anxiety, frustration, guilt and depression, Swaroop et al (2013). Participants expressed their feelings in the following manner:

“It hurts seeing him in this state; it doesn't look like he'll be better than this” (p2).

“I really don't know what to do, I am exhausted, I have no energy left” (p3).

The burden of care severely taxes family members' coping and adjustment abilities and the strain frequently resulting in anxiety, guilt and depression (Navidian & Bahari, 2008)

"I am really trying here, but he doesn't seem to see or appreciate my efforts" (p1).

"I have no one to turn to, I feel like I am losing this battle" (p1).

"Why is God punishing me so much, I pray but it looks like God looks away, I am weak and just useless.....(sobbing)....." (p6).

"It feels like God has deserted me....sobbing.... (p1).

Majority of the participants were very emotional when they expressed their difficulties. Some had lost hope of seeing their mentally ill relative becoming better. Others voiced their frustration at the siblings for not coming on board to help care for the mentally ill relative. Some participants felt as if God had abandoned them, they seemed to be losing faith in him. They believed God was punishing them because their prayers remained unanswered.

4.6 FINANCIAL AND EMPLOYMENT IMPACT OF CARE-GIVING

Swaroop et al (2013) indicated that in an effort to provide the best possible care for a mentally ill relative, caregivers often sacrifice their own physical and emotional needs causing a strain in their lives and wellbeing. Some family members mentioned that they had to take time off work during the week to visit the forensic patient in the hospital as he was very demanding. Swaroop et al (2013) reported that one third of all caregivers involved in the study reported having to balance employment and caregiving responsibilities, two third reported conflicts on having to rearrange their work schedules, working fewer than normal hours and or take unpaid leave of absence from work. Family members raised concerns about the duration of time spent and taken off work to visit the patient in the hospital. Some voiced their frustration about the amount of time they have to devote to caring for mentally ill patient (Ae-Ngibise et al (2015).

"if I take time off from work, I don't get paid enough to buy him stuff that he needs in the hospital". I work overtime sometimes so that I can cope with our financial difficulties". (p5).

" I am afraid that I may lose my job one day, I keep requesting leave days and taking sick days, at times I don't get paid" P3).

Most of the caregivers in the research study were employed and some worked as casuals. Those who had formal and casual employment had to look after other siblings as well in addition to the forensic mental healthcare user. Some participants mentioned that they had to do menial jobs to take care of themselves and other siblings, resulting in greater physical and mental strain. Caring for mentally ill persons can have negative impact on financial and emotional health, Ae-Ngibise et al (2015). Majority of the participants reported the financial constraints as the main challenges because they earned meagre salaries.

"I have to do several piece jobs (casuals) in order to provide for the entire family" (p2).

Some families reported that they had to do several piece jobs in order to provide for both the patient and other siblings at home. Physical strain could lead to exhaustion and enormous stress and deterioration in family caregivers' health. The family organisation and order may fall apart if the breadwinner experiences a severe life adversity such as loss of work, disability or even death.

"I am so tired, I don't get enough time to rest, my whole body aches, still I have to borrow money from other family members and friends" (p3).

"I don't know what I am working for? "The money comes and goes; I borrow money all the time" (P4).

"I can't do anything for myself; I can't even afford to visit other relatives living far away from us" (p6).

"I buy him things all the time, it looks like he gives them away after I go home, I buy him a lot of cigarettes but they don't even last a week" (p4).

The family members' burden of caring associated with financial and employment cost may vary depending on family's socio-economic situations. Most families experience difficulties in having to arrange time off from work to visit the mental healthcare user in the hospital, risking loss of income. The high transport and travel costs incurred as families used varying modes of transport due to distance and locations of the specialist hospitals. Family members have to buy food and groceries for the household as well as for the forensic mental healthcare user, increasing the strain on the family disposable income.

4.7 SUMMARY

The World Health Organisation (WHO) describes caregiving burden as the emotional, physical, financial demands and responsibilities of an individual's illness that are placed on the family members, friends or relatives or other individuals involved with the mentally ill persons. The impact of caregiving stressor on the life of the primary caregiver can have detrimental effects on his/her health and other family members. The primary caregiver with the sole responsibilities for caring for chronically psychiatric patient can lead to chronic diseases, Swaroop et al (2013:30). Financial and employment strain on the life of a primary caregiver compounded their emotional stress and increased the caregiving burden. Majority of the main family caregivers interviewed experienced different emotional, psychological, social and financial pressures which affected the quality of their life and endangered their mental and physical health. In order to reduce the burden of care experienced by the families, interventions like home visit by health care professionals after discharge, education, family therapy and group therapy to help improve physical and mental health of the families(Navidian & Bahari, 2008)

4.8 ANALYSIS OF FIELD NOTES

Field notes are written accounts of data collected during interviews and observations. Fields notes were written immediately following each interview and observation. Field notes were also used to capture any non-verbal cues observed during the interview and served as a possible backup to a missing/ inaudible audiotape. They assisted the researcher in synthesizing and analysing the data (Polit & Beck 2008:404-405). Field notes were significant in assisting the

researcher to identify and interpret feelings, ideas, attitudes and impressions of the families of the forensic patients relating to their experiences of the phenomenon. Some participants displayed anger and frustrations by throwing arms in the air, others blamed themselves for failing to do enough to care for their loved ones. There were some participants who just kept silent for a while before proceeding with the interview. There were clearly visible signs of sadness in their faces. Some were frustrated with siblings for not helping out while others blamed the mental healthcare services.

4.8.1 Observational notes

The researcher was observing and recording verbal and non-verbal behaviours such as hesitation, voice tone and pitch, signs of distress, anger or anxiety. Some participants cried and were clearly overcome by emotions during the interview. During the interview, the researcher made note of the general appearance of each participant: the posture, bearing, poise, anxiety level and how it manifested. The physical layout of the venue was noted as well as the events that took place during the interview. Fluctuations in the mood of the participants, gestures like, facial expressions, eyes, facial hands and body movements used to emphasise points were observed. Reassurance, encouragement and short breaks were given to the participants who were overcome by emotions during interview. The researcher guided the participants in a professional and non-judgemental manner to adhere to the topic.

Kumar (2011:141) describes observation as a powerful systematic and selective way of watching and listening to the phenomenon as it happens while studying the behaviour and personal traits of an individuals. Observations enabled the researcher to gain an understanding and deeper insight into what is being observed.

4.8.2 Theoretical notes

Theoretical notes formed part of the researcher's efforts to attach meaning to observational notes and become part of data analysis (Polit & Beck, 2012:548). These are researcher's interpretation of what is been observed during the interview. Theoretical notes were used to document the researcher's thoughts of what was going on and what's being said or shown by the participants (Polit &

Beck 2008:470) the researcher compared what was being said by various participants in an attempt to elicit common themes. The researcher interpreted the non-verbal cues and the responses displayed by the participants.

4.8.3 Personal notes

These were comments made about the researcher's own feelings, reactions and reflections elicited during the interviews and research process. During the interview, the researcher was emotionally affected by the participants heart felt expression of their own experiences. The researcher expressed empathy and asked reflective questions that focused on the participants emotions.

4.8.4 Demographic notes

Demographic notes provide information about the time, place, date and weather conditions to describe the field where the interview took place (Creswell, 2009:182). The interview too place in three different wards as per telephonic pre arrangement. The visitors rooms were used as interview area and each had a chair and a table. The rooms had adequate lighting and ventilation through two big windows. The interviews were held shortly after winter, hence cool temperature of the room. The windows were slightly ajar to minimise noise and interruptions. The "do not disturb" sign was put outside the door to alert others to keep away from the room.

4.9 CONCLUSIONS

Large amounts of data were generated in this research study and saturation was reached after six participants were interviewed. Participants experienced a great deal of psychological, emotional, physical and financial difficulties in their endeavour of providing care to their mentally ill relatives. Four themes with subcategories emerged following coding, when experiences and needs of families of forensic mental healthcare user were explored and described. The trustworthiness of the semi-structured interview was based on the research purpose and the circumstances experienced. The data collection and analysis assisted in addressing issues of trustworthiness. Chapter 5 will focus on the discussion of the results with reference to and supported by the literature.

CHAPTER 5: DISCUSSION OF THE RESULTS

5.1 INTRODUCTION

The experiences and needs of the families of the forensic patients were described and explored. The data were collected and presented on the experiences and needs of families of the forensic patients. The data collected during the semi structured interviews were analysed and presented in chapter 4. All participants were asked open-ended questions, namely “What are your experiences of living, visiting or caring for a forensic mental healthcare user?” and “what are your needs and how would you like to be supported?” The data analysis, organisation, and interpretation were completed using Tesch’s method of data analysis for qualitative research (Tesch 1992:117)

The conclusion drawn was based on the themes and sub-themes that emerged during the interview of the participants on the experiences and needs of families of the forensic patients. In this chapter, the findings will be discussed and related to the literature review and other studies. Conclusions, limitations and recommendations will be outlined.

5.2 DISCUSSION OF THE FINDINGS

5.2.1 Poor parental expectations

- **Poor supervision and lack of knowledge**

Forensic psychiatric services frequently receive patients who have offended after previously been on psychiatric treatment. Most forensic mental health care users were known by family members to be suffering from some form of mental disorder and to be on medication. Lack of proper supportive structure at home and in the community was cited by participants as a reason that led to the majority of the forensic mental healthcare users defaulting treatment and resulting in psychotic relapse. Some of the participants mentioned lack of information or knowledge about their mentally ill relative’s nature of mental illness and treatment. Some family members described their recollections of the patients’ behaviours and symptoms before the index offence was committed, but were uncertain if that signalled relapse.

Some participants mentioned that their mentally ill loved ones abused substances when they were at home, and thus straining the relationship with other siblings. The use of substances such as cannabis can cause strain in relationship between mental healthcare user and other family members, (Monyaloue, Mvandaba, Du Plessis & Koen, 2014).

Services directed towards supporting the family care-givers of persons with serious and persistent mental illnesses have the potential to improve the outcome for both the care-giver and the mental healthcare user ((Kneisel & Trigoboff, 2009: 821).

5.2.2 Perceived failure as a parent

Families provide a vital support for the relative suffering from serious mental disorder. But, when adverse life events seem to retard the child's progress, a parent tends to blame himself or herself for child's failure. Parents often blame themselves for having not been observant enough to pick up clues of relapse or for failure to notice any significant changes. These parents even scrutinised themselves for the way in which they nurtured their children, and they question their parenting abilities.

Mothers felt that they were despised by the society for not producing kids that met the societal expectations. When a family member became institutionalised a family member or a caregiver attempted to do his/her the best to help in order to compensate for the perceived failure. Family members face many challenges in their attempts to provide care to their mentally ill loved ones, which included: lack of understanding of mental illness, societal pressure and stigma, lack of support from other family members and healthcare professionals, which increased a perceived senses of self-blame and failure.

5.3 STRAINED RELATIONSHIP WITH OTHERS

Most of the caregivers mentioned lack of support from other family members. Participants experienced that their relationship with the forensic patients often had an impact on the relationship that they had with other family members. The disruptions of family and social relations were often experienced by caregivers as the results of their involvement with the forensic patients. The main caregiver

may devote too much time focusing in the forensic patient at the expense of other family members and thus alienating herself/himself from the much needed support of relatives and other family members Ae-Ngibise et al (2015).

Some participants noticed strain in their marriages and relationship with other siblings due to inability to give adequate attention and affection to other family members and to satisfy the partners' emotional needs. They experienced greater negative impact on their social life. Family members more often had to give up their leisure time. Participants described the demanding nature of the forensic patients which caused a strain on the limited family resources. Some family members complained about having to walk long distances and yet patients being ungrateful about things they bought him.

Forensic patients were described by some family members as being threatening and aggressive in their demands which led to the strain in their relationship with others resulting in an increased caregiver burden. Some family members mentioned that they were threatened by MHCU when he was at home. Physical aggression and destructive behaviour by MHCUs posed a threat to family members' well-being and was seen as a barrier to provision of support, (Monyaluoe et al, 2014).

Poor understanding of mental illness by other family members may also contribute towards lack of collective approach to caregiving. Relatives of the primary caregivers may often accuse the forensic patients of being manipulative and too demanding.

The family constitutes an important support system in the care of the seriously mentally individuals. The family collective approach to caregiving can help in reducing the stress of caregiving on the primary caregiver. Healthcare services for mental illness should incorporate aspects of the wellbeing of caregivers (Swaroop et al. 2013).

5.4 EMOTIONAL IMPACT OF CARE-GIVING

Caregivers of the forensic patients often reported experiencing psychological and emotional distress. The chronic stress of caregiving was reported to affect a diverse range of caregivers' health, illness symptoms and use of medication (Shamsaei et al, 2015). The World Health Organisation (WHO) describes caregiving burden as the emotional, physical, financial demands and responsibilities of an individual's illness that are placed on the family members, friends or relatives or other individuals involved with the mentally ill persons. Most participants associated their caregiving experiences with their increased stress levels and the deteriorating health. The unchangeable and unpredictable natures of the patients' behaviour were reported by most participants as the reason for feeling stressed, sad and worried. The families were concerned and worried about the future and prognosis of the mentally ill relative.

Most of the participants reported feelings of frustrations, sadness, depression which impacted greatly on their health in general. Chronic diseases placed a considerable burden on the care of the forensic patients. Objective and subjective burden reported similar variables that contributed to overall caregiver burden. Mental healthcare policies and programs should be sensitive to the stress and burden experienced by families in order to plan and implement a comprehensive treatment program (Swaroop et al.2013:30).

5.5 FINANCIAL AND EMPLOYMENT IMPACT OF CARE-GIVING

The caregivers reported incurring out-of-pocket expenses associated with their responsibilities. The expenses had a huge impact on their disposable income and personal saving. The most common expenses, incurred by more than half of regular caregivers, were related to providing transportation, traveling and buying food and toiletries. The participants reported reduced quality of their lives and family members. Most participants expressed dissatisfaction in having to do additional jobs to increase the families' disposable income. The participants were equally uncomfortable taking more time off to regularly visit the patient in the hospital. Some participants expressed disappointment and frustrations at their inability to meet their own basic needs with the mediocre salary they received.

Caring and visiting forensic patients in a specialist hospital by participants required financial commitments. Participants had to travel long distances to visit the patients. The family members had to buy groceries each time they visited the patient in the hospital. The majority of the participants had dual financial commitments, to the patients and other siblings at home. The financial demands took its toll on the participants' physical and emotional state. Many participants had to do additional jobs in order to supplement their little income.

In the study by Ae-Ngibise et al (2015), there was a strong revelation that the majority of the caregiver burden was attributed to financial problems. The findings were similar to the ones found in countries like United States of America, Ghana, Ethiopia and Nigeria. In Nigeria, caregivers rated financial problem as posing a greater burden than other areas like social stigma, disruption in family routines and subjective stress, Ae-Ngibise et al (2015). The study in the UK indicated that most of the caregiver unmet needs were as results of financial burden.

5.6 LIMITATIONS

- The study focussed only on male forensic patients in closed units and excluded the relatives of the female and male patients in open wards which could have helped to enrich and diversify the data.

5.7 RECOMMENDATIONS

From the findings of this study it became clear that there is a need for an extensive support programme for families of male forensic patients. The following recommendations could be included into such a programme, but because of practical and resource implications for the hospital, systematic implementation of a program is recommended.

5.7.1 Psycho-education

Psychiatric nurses in forensic units must take a leading role in educating families and mental healthcare users about mental disorders, treatment and management of symptoms and social skills training. The compiling and distributing of self-help materials like pamphlets, mini- books on various mental disorders to mental healthcare users, to their visiting family members and relatives could help bridge the gap of knowledge deficit on mental disorders and treatment. Psychiatric nurses to educate other psychiatric nurses on how to conduct therapeutic groups and educational group activities. The policies and guidelines applied in specialist hospitals to make it mandatory for psycho-education to be provided to MHCUs and or family members upon discharge. The auditing of the MHCUs progress reports and clinical files should assess the entry on psycho-education. The policies and protocols on confidentiality and information sharing should be made in such a way that they include family members in the MHCUs' treatment programmes.

5.7.2 Support groups

Support groups can assist the parents and other family members in reaching out to other families in the community with similar difficulties to come together and form support structures. Support groups provide families of the severely mentally ill individuals with the platform and the opportunities to confront their difficulties and sourcing help from each other without fear of prejudice and stigmatization.

Specialist hospital's management system, in collaboration with the social workers and psychiatric nurses can help families to identify support groups structures in their local communities. Psychiatric nurses from the specialist hospital may liaise with community psychiatric nurses, social workers, outreach workers to help families of schizophrenia to form support groups.

The Psychiatric nurses should assess family circumstances in order to evaluate families coping strategies so that support groups can be recommended.

Supportive agents in the community that can help strengthen support groups in the communities to be identified e.g. Churches, local clinics, community social clubs on community development etc.

5.7.3 Family therapy

Family therapy is basically concerned with the relationship with the family members and attempt to deal with expression of emotional symptoms which may signals serious emotional problems within the family (Kneisl & Trigoboff, 2009:823).

Kneisl & Trigoboff, (2009:823) identified five forms of family therapy that can be conducted by clinical specialists or advance nurse practitioners

- *Psychodynamic*: Problems are thought to come from problems with development or current interactions or stressors. This can be used to address strained relationship among families of forensic patients.
- *Family of origin therapy*: To foster differentiation among family members and decrease emotional reactivity and triangulation to help families with highly expressed emotions and with intense reaction to stressors.
- *Structural therapy*: focuses on the family structure, decision making, systems, disengaged families which could help reduce the caregiver burden on a sole family breadwinner.
- *Strategic therapy*: this kind of therapy came about die to believe that problems arise due to inequality, of power, flawed communication and repetitive maladaptive family interaction patterns.
- *Cognitive/behaviour therapy*: focuses on changing thinking and behaviour, problem-solving and development of skills by family members.

5.7.4 Self-help groups

Self-groups are help given to members comes from members themselves with nurse only as a resource person (Kneisl & Trigoboff.2009:812).

Recovery incorporated and schizophrenics for families of mental healthcare users with comorbid conditions of schizophrenia and substance abuse.

5.7.5 Families

Families to be involved in discharge planning and continuous involvement in an on-going treatment plan is required. Psychiatric nurses to share information with families on MHCU's condition, treatment, management of symptoms and dealing with his aggressive behaviour. Families to be referred to a family support agencies on discharge and Information on budgeting and money management programs and support services should be made available and linked with social services established.

5.7.6 Healthcare professionals

Professional assistance in the form of counselling for the families and public awareness campaigns can be organised.

Sourcing of financial support from private, government and non-government organisations can be made to assist families commuting from distant places.

Multidisciplinary meetings should be sensitive to the emotional needs of families of forensic patients by inviting them to meetings and conferences to listen to their concerns.

Family friendly programs and policies that take into considerations the families unique and various circumstances should be made and promulgated.

Psychiatric nurses mandatory post- visit interview with families of forensic patients should be recommended and recorded and feedback given to MDT members.

5.7.7 Suggestions for future research

Further studies using larger sample and including wide diversity of population of female and male forensic patients can be undertaken.

The future research can be pursuit to look into describing and exploring families of forensic mental healthcare users in both closed and open wards to diversify the data. Community mental health services to include home visits by mental community healthcare practitioners and educational programs at the local clinics for families of mentally ill relatives to be made. The mental health system can assist by incorporating cultural/ traditional practices and spiritual support in mainstream healthcare system.

5.7.8 Education for psychiatric nurses

The ultimate goal of any profession is to improve the practice of its members so that service delivery can improve. Proper decentralisation of mental health services in the country and adequate staffing of mental health trained personnel will have a positive impact on communities (Polit, Beck & Hungler 2006). According to the South African Nursing Council, in terms of Government Regulation 425, psychiatric nursing practice provides a scientific basis for cognitive and effective skills that are required for comprehensive nursing in institutional or community settings, of mental health care users, in various age groups, whose capacity to meet their own needs is compromised completely or partially by psychiatric disorders (SANC R425:5 of 25 February 1985). Health professionals should become aware of the need to exercise their clinical judgment and decision-making strategies in order to develop themselves so that quality of patients care can improve. The advanced mental health nurse practitioner should mobilise resources by means of training and learning.

5.8 CONCLUSION

The objective of the study was to explore and describe the experiences and needs of families of male forensic patients in closed units of a specialist hospital in Gauteng Province. The findings highlighted the difficulties that family caregivers experience in their roles of caring for and visiting forensic patients in the specialist hospital. The problems ranged from self-blame as parents and questioning their parenting capabilities, to emotional distress, strained relationship with others and the financial and employment impact of caregiving. Not only did participants in this study clearly indicate their need to be involved in the therapeutic programmes to support their family members, but what is reiterated most, is the extent of the trauma experienced by these families and the effects on all aspects of their lives.

There is strong empirical evidence that living with, caring or visiting chronically mentally ill individuals can adversely impact family members and reduce their quality of life. Empowering family caregivers through open communication and information sharing about mental healthcare users' conditions and treatment can help to alleviate the stress associated with caregiver burden. Family support should be based on the following key elements: illness education, emotional support and training on how to cope with the illness as well as the symptoms and related problems.

The exploring and describing the experiences and needs of families of male forensic patients in a specialist hospital led to the formulation of the recommendations that support the family caregivers and mental healthcare users. These recommendations can be used by psychiatric nurses in the specialist psychiatric hospital to support families of the forensic patients.

APPENDIX A

EXPLORING EXPERIENCES AND NEEDS OF FAMILY MEMBERS OF FORENSIC PATIENTS

FAMILY MEMBERS' CONSENT FORM

You are hereby requested to participate voluntarily in the research study entitled: "The experiences and needs of families of male forensic patients in a specialist hospital".

The researcher will conduct the interview which is expected to take approximately 20--45 minutes. A tape recorder will be used; the researcher will need your permission to record the interviews. The interview will take place in a quiet and private area of the ward.

Participation in the research study is entirely voluntary. Should you wish to withdraw from the study at any time, you will not be penalised or suffer any loss of benefits that you may be entitled.

No benefits will be derived from participating in the study. However, once the study is completed it will help to clarify the role that psychiatric nurses can play in understanding the needs and experiences of family members so that healthcare delivery can be improved. You or your relative/ significant other will not be identified in the report and you may have access to the results if you so desire.

The research ethics committee of the University of Johannesburg, the Department of Health and Weskoppies Hospital have approved the study.

Should you have any further inquiries you may contact University of Witwatersrand Human Research Ethics Committee at 011 717 1252/ 011 717 2700.

Thank you for taking time to read this letter. Should you require further information, contact me BJ Pule at 0742554948.

The Research study and my rights have been have thoroughly and verbally communicated to me and I understand what my participation entails. I voluntarily agree to participate in this research study.

Participant's signature

Date.....

Researcher's signature

Date.....

APPENDIX B

EXPLORING EXPERIENCES AND NEEDS OF FAMILY MEMBERS OF FORENSIC PATIENTS

MENTAL HEALTH CARE USER INFORMATION LETTER

Dear.....
(Name of mental health care user)

My name is Bashu Pule; I am a postgraduate student at University of the Witwatersrand pursuing Master of Science studies in advanced psychiatric nursing. I wish to conduct a research study on experiences and needs of family members/significant others of male forensic patients at specialist psychiatric Hospital. I would like to request your permission to include your family member or significant other in my studies.

The purpose of the study is to find out about the experiences and needs of your family member or significant other. Studies show that family members or significant others may experience emotional and physical distress when their needs are not adequately met. Psychiatric nurses can play a vital role in identifying these needs and experiences in order to provide adequate support for you and your family or significant other.

Should you grant permission for your family member or significant other to take part in the studies, I will ask you to sign a consent form. I will be conducting the interview and it is anticipated to take approximately 20-45 minutes. The interview will be conducted in a quiet room of the ward.

Participation is entirely voluntary. Your family member may choose to participate or withdraw from the study at any time without any penalty, loss of benefits, and your healthcare will not be adversely affected.

No benefits will be derived from the participating in the study. However, I hope that the outcome of will help to clarify better understanding of family needs by psychiatric nurses in order to improve the quality of care. Neither you nor your family member or significant other will be identified in the report.

The research ethics committee of the University of Johannesburg, the Department of Health and Weskoppies Hospital have approved the study.

Should you have any further inquiries you may contact University of Witwatersrand Human Research Ethics Committee at 011 717 1252/ 011 717 2700.

Thank you for taking time to read this information letter. Should you require further information, contact me at 012 319 9634.

Mental healthcare user's signature

Date.....

Researcher's Signature

Date.....

APPENDIX C

University of the Witwatersrand
Faculty of Health Sciences
Department of Nursing Education
7 York Road
Parktown
2193

The Chief Executive Officer
Weskoppies Hospital
Ketjen Street
Pretoria west
0001
Dear Sir/Madam

REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT WESKOPPIES HOSPITAL

I, B J PULE, a postgraduate student at University of the Witwatersrand pursuing Master of Science studies in advanced psychiatric nursing, would like to request permission to conduct research at Weskoppies Hospital. The theme of the study is **“Exploring and describing experiences and needs of family members and significant others of adult male forensic patients at a specialist psychiatric hospital.** The study will be conducted under supervision and guidance of Dr G Langley and Professor of University of Witwatersrand Nursing School.

Family members or significant others suffer emotional and physical stress when a relative with mental illness is arrested for a criminal offence. Their distress could be attributed to separation, poor adaptation to change, inadequate coping skills, lack of support, stigma as well as family caregiver burden. The empirical evidence indicates that the provision of supportive services by psychiatric nurses would assist the family members or significant others in meeting these needs.

Therefore, the study seeks to explore and describe the experiences and needs of family members and significant others of adult male forensic patients in specialist psychiatric hospital. The ultimate aim is to develop a guideline for psychiatric nurses in forensic wards to provide adequate support to family members and patients.

I intend to conduct the research study once permission is granted. No names of patients and family members will be revealed in the report and the information will be treated with utmost confidentiality. Purpose sampling will be used to collect data. Data will be collected until saturation is reached. Interviews will be conducted on selected wards and will be audio taped. Participation in the study is voluntary and can be terminated by participants without recourse. Consent form will be signed by participants prior to interview. Information leaflets detailing the research study and its intended purpose will be given out to participants before interview.

Should you have any further inquiries you may contact University of Witwatersrand Human Research Ethics Committee at 011 717 1252/ 011 717 2700.

For more information, the undersigned can be contacted on the following mobile phone number: 074 255 4948.

Yours Sincerely

Bashu Pule

MSc Student

APPENDIX D

INFORMATION LEAFLET AND PARTICIPANT INFORMED CONSENT

Title of the study: experiences and needs of family members of male forensic patients.

Dear participant

1. Introduction

I invite you to participate in a research study. This information leaflet will help you to decide whether you want to participate. Before you agree to take part, you should fully understand what it involves. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask the interviewer.

2. The nature and purpose of this study

The aim of this study is to obtain clear understanding of the experiences and needs of family members/significant others of male forensic patients. The following methods will be described: research setting, population and selection of participants, purposive sampling, method of data collection, which will be done by means of semi-structured interview, and data analysis.

3. Explanation of procedures to be followed

This study involves the interviewing of participants by the researcher, which will last about 20 to 45 minutes. The central questions that the researcher will ask are: "What are your experiences of living, visiting or caring for a forensic mental healthcare user?" and "what are your needs and how you like would to be supported?"? An audiotape recorder will be used to record information and the interviewer will also write down some notes.

4. Risk and discomfort involved

There might be minimal risks involved in the study. Some of the questions that are going to be asked may make you feel uncomfortable, but you need not answer them if you do not want to. In case of emotional discomfort, participants will be referred to a relevant professional for counselling to ensure full support.

5. Possible benefits of the study

Participants are going to benefit directly from the study; participants will have an opportunity to share their experiences. The results of the study will enable people to gain understanding of the experiences and needs of people with family members, relatives or significant others who are forensic patients.

6. What are your rights as a participant?

Your participation in this study is entirely voluntary. You may withdraw at any time during the interview without giving any reason. Your withdrawal will not affect you in any way.

7. Has the study received ethical approval?

This study has received written approval from the Research Ethics Committee of the faculty of Health Sciences at the University of Witwatersrand, the University of Pretoria and the Chief Executive Officer of Weskoppies Hospital. Copies of the approval letters are available if you wish to have one.

8. Information and contact person

The contact person of the study is BJ PULE. If you have any questions about the study, please contact him on 074 255 4948. Alternatively, you may contact my supervisor, DR Gayle Langley at 011 488 4270.

9. Compensation

Your participation is voluntary. There is no compensation for participating in this study.

10. Confidentiality

All the information that you give will be kept strictly confidential; only the researcher, my supervisor, the coder and ethics committee will have access to data. Once we analysed the information, no one will be able to identify you. Research reports will not include any information that might identify you.

11. Participant’s consent to participate in the study

I confirm that the person asking my consent to take part in this study has told me about the nature, process, risks, discomforts and benefits of the study. I also received, read and understood the above written information regarding the study. I am aware that the results of the study, including personal details, will be anonymously processed in research reports. I am participating willingly. I had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to withdraw from the study and that my withdrawal will not affect me in any way.

I received a signed copy of this consent agreement.

Participant’s name(Please print)

Participant’s signature..... **Date**.....

Researcher’s name(Please print)

Researcher’s signature.....**Date**.....

APPENDIX E



Enquiries: Mrs. M A MAbena
Ref No.:

Weskoppies Hospital
Private Bag X113
PRETORIA
0001
SOUTH AFRICA
Tel No. +27 12 319 9680/1
Fax No. +27 12 319 9697

Mr B J Pule
Professional Nurse

PERMISSION TO CONDUCT RESEARCH

1. Your letter to request for permission to conduct research at Weskoppies Hospital refers.
2. Your request to conduct research on the topic "Exploring and describing the experience and needs of family members/significant others of male forensic patients in Specialist Psychiatry Hospital" is approved.
3. The Internal Policy on Ethical Research in Weskoppies Hospital (GN40) refers.

Yours sincerely

A handwritten signature in black ink, appearing to be "M A Mabena", written over a dotted line.

Mrs. M A Mabena
Chief Executive Officer
28/07/2014

APPENDIX F



HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140235

NAME: Mr Bashu Joseph Pule
(Principal Investigator)

DEPARTMENT: Nursing Education
Weskoppies Hospital

PROJECT TITLE: Exploring and describing the experience and needs
of family members/significant others of Male
Forensic Patients in Specialist Psychiatry Hospital

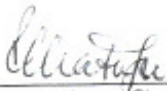
DATE CONSIDERED: 28/02/2014

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Prof Gayle Langley

APPROVED BY:



Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 23/04/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G



Faculty of Health Sciences
Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172040

Reference: Ms Thokozile Nhlapo
E-mail: thokozile.nhlapo@wits.ac.za

Mr BJ Pule
P O Box 58986
Karenpark
0118
South Africa

13 June 2014
Person No: 676905
PAG

Dear Mr Pule

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Exploring and describing the needs and experiences of family members or significant others of male forensic patients in a specialist hospital* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

A handwritten signature in cursive script, appearing to read 'Sandra Benn'.

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX H

Verbatim transcript of the semi- structured interview with a Participant

Interviewer: Good afternoon mam

Participant: Good morning Bashu

Interviewer: How are you today?

Participant: Life goes on Bashu

Interviewer: Glad to hear you are okay

Participant: I am never okay...mmmm...Bashu! it looks like I was **born to struggle forever**. (Looking away).

Interviewer:mmmm.....

Participant (interrupting): Coming here all the time....eish.....**it's like never ending battle**.

Interviewer: Tell more about your experiences with your son, how is like living with him, coming here and seeing him.

Participant: I feel really **sad**, to see him here, it is not what one would want for her child, I wanted a good future for him, I wanted him to be something big in life. Being my last born, it is quiet troubling... I must say.

Interviewer: It seems you had great things planned for him?

Participant: Yes indeed ...ummmmm..... (Silence) emotional

Interviewer: (Silence)

Participant: You see Bashu.....mmm.....my son (**emotional**), my son has been ill for many years, actually he started behaving bizarrely when he was 19, and he never finished school. He has been on medication since his teen until now, but nothing could have prepared me for the crime he committed.

Interviewer: What kind of difficulties did you experience with him growing up?

Participant: He had a normal childhood.....mmm.....everything was normal with him. He attended.....Mm.....primary school and never repeated a grade until he was in high School.....”

Interviewer: I notice you seem upset to talk about his high school years.

Participant: Yes, that’s exactly where all the trouble started

Interviewer: What kind of trouble?

Participant: He was **aggressive** towards other kids at school...mmm...I remember in grade 11...yes ...grade 11, he lacked concentration and often talked to himself. He failed grade 11 twice and we just gave up, he quit school altogether

Interviewer: As an adult, did things change for the better, for your son?

Participant: Not at all, he got worse.....mmmm.....**fighting** on the street.....mmm.....stealing from us and neighbours. He was hated by everybody in the street.....mmmm....his mental state got worse, he could not sleep....he talked to himself and even singing loudly at night when we were asleep. Medication they gave him at the local clinic didn’t work

Interviewer: Was the medication for mental illness or something else?

Participant: Yes, he **took medication** for years for his psychosis

Interviewer: Do you think his psychosis drove him to do bad things?

Participant: Indeed, though we suspected at first that he was bewitched, we took him to three traditional healers, but he got worse

Interviewer: Did he continue with his medication even when you took him to the traditional healers?

Participant: No, I think....mmm....let me see....mmmmm..... he **stopped taking his medication** long before we took him there?

Interviewer: Was the medication not good for him; were you aware that he was not taking his medication?

Participant: He complained about being always **tired** and **sleepy**, we went back to the clinic; they reduced the dosages with no help. He complained but ...um.....i insisted that he continued taking it; I guess he was not taking it regularly as he was alone at home during the day

Interviewer: Being alone at home and he hid his medication or something and pretended?

Participant: I suspected that he did, I never checked his medication to make sure

Interviewer: Was he ever arrested for stealing things?

Participant: Yes, he was arrested many times.....ummmm.....i lost count really

Every time the police....umm...arrested X....he was transferred to the local psychiatric hospital.....mmm.....until two years ago when he fought with the man in the street and killed him

Interviewer: You seem very set to talk about that

Participant: Yes....we were all in shock at home...It was like.....Ummmmm.....i was absolutely numb with shock. He is here now.....i look at himmmmmm.....i am like; my son a killer? It's so surreal even today.

Interviewer: How often do you come here to see him and how do you feel doing that

Participant: I come here mostly on weekends, but at times during the week...ummmm.....you see I do **piece jobs** (casuals)...whenever I have extra cash I would just come and see him. Most of the time.....ummmm.....he would call me to give a long list of his grocery

Interviewer: What kind of things do you buy him?

Participant: Heummm....**demands** cigarettes and food grocery all the time, I spend all my money on him and he does not seem to appreciate it.

Interviewer: Do you have any **support** from home, do other family members or relatives help?

Participant: They hate him, my other children hate him, and they don't want to see him coming home.ummm....you see he used to be extremely aggressive when he was at home. My daughter came here once to see him, she was so upset when she got home because apparently he was **irritable and demanding**.

Interviewer: Do you actually know what is wrong with your son? Do you know what kind of mental disorder he has?

Participant: I have **no clue** at all. I was never told anything about his illness or even the medication he receives. My son used to be admitted in the very same hospital for years ...ummmm.....I used to pick he up for weekend leave and when he was discharged.....mmmm.... nobody told me anything about his illness or his medication.....I regreti really I do.

Interviewer: What do you regret about?

Participant: I feel like....you... knowummm Bashu.....that I somehow **failed my son**. I should have asked about his illness, I should have arranged for someone to be at home with him.....none of this could have happened....bad parenting, what kind of a parent am i?

Interviewer: Do you ever talk to nurses here.....umm... in this ward about your son?

Participant: **Very rarely**, they seem always busy.....ummm.....one day one of the male nurses told me that my son has schizophrenia.....I saidschizo....what? He then rushed off somewhere before explaining much.

Interviewer: How are you overall feelings about coming here to see your son?

Participant: Honestly, **I feel sad** all the time seeing him like this, he appears dirty and stiff at times. I work most of the time...ummm..... I don't get much rest. I find it **hard to cope** on my own, other siblings don't help. I take medication for depression and high blood pressure. I am.....ummm... walking dead basically, sometimes **I wish I was dead**. I am seriously on my own here. You know what?you pray...pray....pray....It's like God has abandoned me (silence).....
(Sobbing)

Interviewer: Do you currently see someone, a professional counsellor to help you through this?

Participant: apart from my Doctor at the clinic I talk to my pastor almost every day. But my doctor suggested that he would refer me to the psychologist at the hospital.

Interviewer: We are almost done with the interview; do you have any question you may want to ask me?

Participant: No, I am okay, thank you for listening to me.

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