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Living with mental illness: A descriptive study of individual adult experiences of living with mental illness in Zomba, Malawi

By

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A Thesis Submitted in Partial Fulfilment of Requirements

for The Award of

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School of Nursing, Edith Cowan University

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USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Abstract

The purpose of this study was to examine the experiences of mental illness in the adult Malawian context. Using the interpretive paradigm, content analysis was used to uncover the lived experiences of mental illness. This study was based on the philosophy that meaning of a phenomenon is best understood if studied within its specific context and within Parse's theoretical framework.

Two to four percent of the global population share the experience of mental illness, however, little is known of individual experiences within the Malawian context. Much of the literature has focused on the physiological aspects, causes, and therapies involved in managing mental illness. Given the less than optimal availability of literature on the topic, this descriptive study was conducted in Zomba, Malawi. A convenience sample of 10 adult outpatients (six women and four men) with schizophrenia or bipolar affective disorders were interviewed to elicit descriptions of experiences of their conditions. The participants' mental conditions were considered stable at the time they were attending the community mental health services. As a result of their experiences, the researcher categorised the participants' descriptions as follows; view of the self, view of their illness, other peoples' views, stigmatisation and discrimination, loss, suffering and distress, fear, gender issues, and coping strategies.

The findings showed that this study made a contribution to nursing knowledge that is relevant to the understanding of mental illness. It is possible that this knowledge may also form the basis for recommendations in nursing care and counselling services for the mentally ill persons in Malawi.

Declaration

I certify that this thesis does not incorporate, without acknowledgment, any material previously submitted for a degree or diploma in any institution of higher education and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in text.

Ivy Joanna Gertrude Lekera

Date: 11 November, 1997

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CHAPTER ONE

Introduction

"Definitions cannot begin to explain the overwhelming experience of living with mental illness. Diagnosis, symptoms, and determined treatment only provides a glimpse into this experience. Beyond this is the personal account, the very human response to illness, and how those individuals and their families make sense of, cope with, and adapt to the symptoms and disabilities of mental illness" (Kleinman, 1988, p. 237).

This thesis describes a study of the meanings of the experience of 10 participants with mental illness living in Zomba, Malawi. The study is based on the assumption that human beings will always find meaning or strive to find meanings in any situation they are in, regardless of the circumstances (Frankl, 1992). Accurate information on the meanings of the experiences of people with mental illness would be gained, particularly for health care professionals in Malawi.

In the Malawian tradition, the image of mental illness is one of the very disturbed, possibly aggressive, half naked man uprooting crops, burning houses, or walking down the white line on the road from Zomba to Blantyre. Such a person would be regarded with fear and either be avoided at all costs, or strenuously restrained and handed to the police (Wilkinson, 1992). Some governments have adopted many policies and plans regarding care of the mentally ill. Such plans and policies have been designed to ensure that, wherever possible, people with mental illness are able to enjoy the same opportunities as other citizens (National Mental Health Strategy, Australia, 1996). Decentralisation of mental health services was one of the strategies which was adopted by many governments, including Malawi. Decentralisation is the movement of mental health care services from large state hospitals to the community (Hazelton, 1993). It is believed that decentralisation reduces the stigma of mental illness but what

does the individual with mental illness think? The perception of the condition and needs of the individual in the Malawian context, and many other settings has not been ascertained.

Background of the Study

This study is based on an increasing concern for Malawi people with mental illness and their quality of life within the changing mental health system. Mental illness is an illness in which the main symptoms are mental rather than physical, usually temporary and treatable (Stuart & Sundeen, 1995). Mental illness is a worldwide problem. A World Health Organisation Report (1991) stated that 2% to 4% of the global population is currently suffering a mental illness of some sort. It is also projected that mental health problems will affect more than 20% of the adult population in their lifetime and between 10 to 15% of young people in any one year in Australia (National Mental Health Strategy, Australia, 1996). In addition 1.5 million people in United States of America (USA) in 1987 were reported mentally ill (Crosby, 1987). The figures indicate that mental health problems are indeed a worldwide concern.

Accurate statistics on mental illness in Malawi are not available due to the fact that culturally, mental illness is most commonly believed to be caused by witchcraft or possession by evil spirits (Mbuluma, 1990). As a result, Malawian people do not seek medical help promptly. The traditional healers, the first line of help, are sought when the relatives of an individual notice a mental health disorder (Wilkinson, 1991). The formal mental health service or the professional sector of health only see a certain percentage (Peltzer, 1987). According to the Community Health Science Unit (CHSU) (1994), 38,328 of the 11 million people living in Malawi had a mental illness of one type or the other. Of these people, 2,145 (16%) resided in Zomba, Malawi. The figures

may be somewhat inflated with respect to the population of Zomba because the main institution for the mentally ill is situated in the district, to which most of the mentally ill from the country are referred. After discharge from the hospital some of the patients do not return to their original homes, thereby increasing the numbers of the mentally ill in Zomba.

Even though mental illness in Malawi, and most of Africa, is believed to be caused by witchcraft, studies by Ben-Tovim (1987) and Edgerton (1966) indicated that the causes of mental illness are the same in developed and developing countries. The difference lies in the interpretation of the illness and meaning of the experience related to the different cultural backgrounds.

The Problem

There are many approaches to the management of the mentally ill and many more are being introduced. Most of the management approaches emphasise the influence of environmental stress on the course of the illness. Relatively neglected is the internal experience such as the source of stress and anxiety (Hatfield, 1989). Internal experiences of the mentally ill reveal the wisdom and creativity with which patients have come to terms with their illness. Hatfield asserts that patients' descriptions of their experiences supply valid and useful data for understanding and helping individuals to cope with daily life by providing appropriate interventions. For this reason it was necessary for the researcher to conduct a study to find out the descriptions of mental illness from individuals with mental illness in Malawi. The nurses in the mental health sector in Malawi may benefit from the findings of such a study and incorporate them in formulating realistic and more effective nursing interventions.

Mental illness has always had socio-cultural connotations. In order to provide culturally acceptable interventions, mental illness should be studied in the context in which it is occurring (Banes, 1983). Crawford (1995) argued that mental health staff trained in a Western model of mental illness can never hope to gain understanding of and empathy with their African patients. She further argued that improvement of psychiatric care in South Africa depends on collaboration between health care professionals operating from both traditional and Western belief backgrounds. Mental illness is linked to society and culture. It is therefore important to study the experiences of the mentally ill in their natural environments and to study experiences that are not well understood in the Malawian context. The problem is data like this is not available in Malawi and the nursing care provided to the patients is Western-nursing oriented and not African-culture oriented. Such nursing care might not be culturally relevant and prove to be non effective.

Purpose of the Study

The purpose of this study was to describe the experience of being mentally ill in an adult population in Zomba, Malawi. The analysis of this study will provide knowledge of the meaning of the experience of this population of the mentally ill. It will also provide additional knowledge in mental illness in Malawi and help nurses to provide culturally acceptable care for the mentally ill.

Objectives

The objectives which guided this research study were derived from Parse's (1981) theory of human becoming. This theory was chosen because it will be used in the second level analysis of data. The objectives that guided the study included the following:

1. To describe the major life changes related to mental illness of individuals having schizophrenia or bipolar affective disorder.

2. To explore the patterns of relating and strategies for coping of persons living the experience of schizophrenia and / or bipolar affective disorders.

3. To describe the changing perceptions of persons living with mental illness.

4. To use the information to add to the growing body of knowledge in nursing mentally ill adults based on the Malawian experience.

Significance of the Study

The study seeks to add to the knowledge base for the psychiatric nurse whose major responsibility is to assist patients to find meanings in their experiences and to cope with everyday life. This study will contribute to the knowledge base in the following ways. Firstly, it acts as a baseline for further research. Research in mental health in Malawi is in its infancy. So far there is little known about the meaning of experiences of the mentally ill in the Malawian context. McFarland and Thomas (1991) defined meaning as the interpretation given to a particular life experience by the individuals undergoing that experience.

Secondly, it is believed that experiences are better understood if studied in the context in which they are occurring. This study will offer an opportunity for others to understand mental illness from the perspectives of the individual suffering in the Malawian context. Nursing interventions can therefore be offered that are appropriate to the persons with mental illness in this particular setting.

Thirdly, research in the interpretive paradigm in Malawi, just as in the world at large, is gaining recognition. The results of this study will therefore act as encouragement for other nurses to conduct their studies in this paradigm. The meanings

of experiences are understood more if the person living the experience is the one describing the experience. This is consistent with nursing science which is striving to study human beings within the context of their experience (Chinn, 1994).

Definitions of Terms

The term mental illness is defined in relation to two subcategories, schizophrenia and/or bipolar affective disorder or manic-depressive disorder.

Schizophrenia. A general name for a group of psychotic reactions characterised by withdrawal, disturbances in emotional and affective life, depending on type, hallucinations, delusions, negativistic behaviours and progressive deterioration (Stuart & Sundeen, 1995).

Bipolar affective disorder or manic-depressive disorder. Mood disorder alternating between manic and depressive episodes (Stuart & Sundeen, 1995).

The traditional healer. "... is a person who is recognised by the community in which he lives as competent to provide health care by using vegetable, animal, and mineral substances and certain other methods based on the social, cultural and religious background, as well as on the knowledge, attributes and beliefs that are prevalent in the community regarding physical and mental being and the causation of disease and disability" (Ayodele Tella, 1987, p. 2).

Organisation of The Thesis

Chapter One provides an introduction and a discussion of the significance of the study. The purpose and objectives for the study are also outlined, followed by the definitions of terms related to the study. Chapter Two consists of a literature review of the mental health service of Malawi and literature related to the lived experience of schizophrenia and bipolar affective disorders or manic depressive disorders. Chapter Three describes the theoretical concept underpinning this study. Parse's theory of human becoming was

the theory of choice in this study. Chapter Four describes the methodology which includes research design, participant selection, the procedure, data collection, data analysis, confirmability of the qualitative data, limitations of the study, and ethical considerations. The findings of the study are described in Chapter Five. A discussion of the findings and its related literature, findings and theoretical focus, implications for practice and research follows in Chapter Six.

CHAPTER TWO

Literature Review

This literature review has been organised according to the following three purposes. Firstly, it situates the study within a context of the meaning of mental illness according to the Malawian perspective. Secondly, it critically examines current literature on the experiences of selected mental illness worldwide. Thirdly, the literature review identifies gaps in knowledge on the experiences of mental illness based on the individual's perspective.

The Mental Health Service in Malawi

Historical Perspective

There have always been mentally ill people in Malawi, just as in any society. From time immemorial, such people have been given some kind of care, even if it was solely "custodial", that is keeping them in a safe place and under supervision. Generally there has also been limited recognition of mental disorders and limited attempt by communities to deal with it (Horace, 1936; Wilkinson, 1992). In the beginning, mental illness was associated with aggressive behaviour. There have always been other presentations of mental disorder which are not always recognised, like the silent withdrawn individual, the child running off into the bush, or the adolescent who, almost unnoticed, begins to lose concentration and fail in studies. People have always recognised the obviously aggressive mentally disturbed individuals in the community and, traditional treatments have been available as long as there have been traditional healers (Ayodele Tella, 1987). According to this author, a traditional healer is a person recognised in the community as a competent provider of health care using vegetable,

animal, and mineral substances, and other practices such as exorcism, depending on his/her social-cultural background. People in Malawi, as in most African countries, do not only find therapy but also a ready explanation for their illness as indicated by the traditional healer (Salima, 1987).

It was against this background that the mental health service of Malawi began. It was not in the community or hospital, but in the Central Prison in Zomba. The staff and prisoners found that they were disturbed by a number of inmates who were clearly mentally ill owing to their aggressive behaviours and inappropriate communication patterns. It was decided that it would be much better to separate those prisoners from the mentally sound individuals (Mbuluma, 1990). The Zomba Lunatic Asylum came into being in 1910 as a wing of the prison, and was monitored by wardens and officers from the prison. It remained under the prison authorities until 1951. It was not until 1955 that a psychiatrist was appointed. In 1913 there was a debate on the Native Lunatics' Ordinance and the Acting Government Secretary explained that the legislation was designed to ensure that the lunatics were treated properly during detention, and with the consideration and humanity which their unhappy situation demanded (Wilkinson, 1991). It was argued that the asylum was just a wing of the prison, separating the criminally insane from normal prisoners, and no real treatment was offered until the 1930s. Most cases of mental illness continued to be treated by traditional healers in the communities.

Present Trends in Mental Service in Malawi

The researcher's experience as a mental health nurse in Malawi indicates that despite the suffering and the great personal financial costs resulting from mental illness, the community has not always recognised the needs of people with a mental illness, or

respected their rights to live independent lives. Traditionally, people with a physical illness evoke community concern and sympathy, and their needs are readily recognised. They actually participate in their own care. However, people with a mental illness are not usually so fortunate. In the past, the more severely affected people were isolated and treated in psychiatric institutions, and had little opportunity to decide where they wished to be placed, since at that time the psychiatric institution and prison were one and the same. During the last decade, the situation has changed and, although some people with severe mental illness still require hospitalisation, the emphasis has been treating and supporting people with mental illness in their own communities. This was recognised as the decentralisation of mental health care (Flaskerud, 1986).

For the past 20 years, the concept of decentralisation of mental health services has spread throughout most of the countries in the world. This is the movement of mental health care from large state hospitals to the community (Talley & Coleman, 1992). The purpose of this move was to try and reduce the stigmatisation attached to mental illness. Decentralisation has been identified as another major change in the mental health care system since the era of psychotropic drugs and when large mental hospitals were formed in the early nineteenth century. In the early nineteenth Century, it was argued that people with mental illness required to be institutionalised and cared for in an asylum (Flaskerud, 1986). In Malawi, the concept of decentralisation was appealing because it was thought that it would increase the number of the mentally ill who use the formal mental health care service without being transferred into institutions, thereby reducing the stigma of mental illness (Mbuluma, 1990). Stigma means a mark or sign of shame, disgrace or disapproval, of being shunned or rejected by others (Stuart & Sundeen, 1995). It emerges when people feel uneasy or embarrassed to talk about

behaviour they perceive as different from others (Roper & Anderson, 1994). Table 1 shows a steady increase in the numbers of mentally ill persons who utilised the mental health services from 1991 to 1994. It also shows that the most common diagnoses of mental illness in Malawi are psychoneurosis and psychosis. Schizophrenia and bipolar affective disorder fall under the group of psychosis. Whether decentralisation is indeed reducing stigma or not is not yet known because the people suffering the phenomena have not been questioned in the Malawian setting until recently.

Table 1

Incidence of mental illness in Malawi 1991-1994

	1991	1992	1993	1994
Psychoneurosis	17,300	12,152	22,331	28,416
Psychosis	6,286	4,382	7,404	9,904
Return Rates (%)	47	43	57	69

From Basic Health Statistics Report 17, Community Health Science Unit (CHSU), Lilongwe.

The Health Care System in Malawi

The health care system is defined by Kleinman (1980, p. 24) as "the relationship between illness and the responses to it, the individuals experiencing it and treating it, the social institutions relating to it, and the culture in which it occurs". According to Peltzer (1987), the health care system cannot be separated from culture and society. The health care system in Malawi can be divided into three sectors: the popular sector, the folk sector and the professional sector (Kleinman, 1973).

The popular sector is, according to Kleinman (1980), the lay, non-professional, non-specialist, popular culture arena in which illness is first defined and health care

activities initiated. Self-treatment in the form of herbal preparations, patent medication and over-the-counter drugs used by individuals and family members is often the first therapeutic intervention resorted to by most people across a wide range of cultures.

The folk sector of health care can be characterised as non-professional and non-bureaucratic. It involves consulting traditional healers, witch doctors and/ or spiritual healers. Treatment of illnesses consists of herbal drinks and spiritual exorcism (Ayodele Tella, 1987). Today, the popular and folk sectors still provide 80% of the rural population of Africa with health care (World Health Organisation, 1991). Since 90% of the Malawian population in 1981 lived in rural areas, it was expected that the popular and folk sectors should play a significant health care role. The popular and folk sectors together form what is called the traditional sector. Since 1975, these sectors have been receiving increasing attention, and attempts have been made to integrate them into the national health care system (Msukwa, 1981; World Health Organisation, 1976a & b). The reason for the integration was that most doctors and traditional leaders agreed that exclusive reliance on Western methods of health care does not meet the demands of the country considering its cultural orientations and individual beliefs (Ministry of Health, Malawi, 1976).

The professional sector of health care, comprising the organised healing professions, consists in Malawi of modern scientific medicine (Peltzer, 1987). Even though there is an increase in the number of mentally ill persons who utilise the professional sector of health care, Kapapa (1980) argued that the treatment of such disorders is based on Western values that are specific to the cultures of Europe and North America. Salima, (1987), Warner (1983), and Williamson (1975) further argued that Western psychiatric modalities of care cannot be applied to the Malawian context

without taking culture-specific definitions of causes and therapy of psychosocial disorders into consideration. After consulting a traditional healer, the relatives of the mentally ill person usually consult the professional sector. They either combine the therapies or stop the traditional ones for a while (Ayodele Tella, 1987; Upvall, 1992).

Entry into the Professional Health-Care Service

In Malawi, as in most other countries, mentally ill persons are protected by law through the government's mental treatment acts. Because of the nature of the illness however, patients are prone to abuse, both physically and psychologically, from the community and their families (Burdekin, Guilfoyle & Hall, 1993). Most of the time the patients' rights are not considered. According to laws in Malawi, the Mental Treatment Act 1\1968 indicates that there are three ways that individuals enter into the country's formal system. Firstly, any person of 16 years or more who is willing to submit to treatment for a mental disorder could be received as a voluntary patient into the health care system. Secondly, any person who is suffering from mental disorder and likely to benefit by temporary treatment in a mental hospital, but is incapable of making a choice about treatment may enter the health care system on receipt of a written application from a relative or spouse. A person can remain in the institution until well. A third way is by application for a Reception Order from the magistrate, certifying the need for hospitalisation, along with a requisition for admission from the relative and a medical certificate (Laws of Malawi, The Mental Treatment Act, 1968).

Regardless of the availability of the Mental Treatment Act (1968), there remain cultural and legal conflicts in the Malawian community. The relatives are usually in the forefront of deciding what is good for their mentally ill relative. According to the researcher's experience as a mental health nurse in the Malawian setting, few patients

are received as voluntary patients in the mental health service. This usually deprives them of making their own informed decisions about consulting either a traditional healer or going straight into the professional mental health service. In the experience of the researcher, statements such as "My father thought that I was mentally ill and decided to take me to the traditional healer first; when there was not much improvement he took me to the hospital", have been frequently made during the initial interviews of patients on admission to a psychiatric institution. Such statements indicate what little say the mentally ill individual has regarding personal care and treatment.

Cultural Conceptions of Mental Illness

Cultural-specific definitions

To understand more about the study results, the descriptions which emerged, and to provide a framework for discussion, a brief description of the cultural conception of mental illness in the Malawian context is provided. The literature was sparse, however, to add weight to the discussion, literature from other cultures was also examined.

From the researcher's observations and experiences, the cultural definition of mental illness 'Kuzungulira mutu', which could be translated as 'nervous breakdown', is an important conceptual basis for the acceptance of the mentally ill in this community. There are other concepts which are used in other parts of the country. Terms such as 'vimbuza', and 'majini' are used like 'kuzungulira mutu', in Northern Malawi and Southern Malawi respectively (Peltzer, 1987), but these are more to do with spiritual possession, and discussion on these two concepts is beyond the scope of this study. There is also another folk concept, 'misala', meaning mental illness. 'Misala' is usually

associated with the more severe symptoms of mental illness such as chronicity, permanency, and stigma (Wilkinson, 1992).

'Kuzungulira mutu' or nervous breakdown is a term used by many Malawians to refer to a wide variety or array of emotional states. According to this folk conceptualisation, it afflicts people who are facing difficulties in their everyday life such as family disruption and economic hardships. It is a socially acceptable response to high levels of stress. This is unlike 'misala' which is not talked of freely in the community. Unfortunately, the researcher could not find relevant literature to support this notion. However, discussions with other Malawian psychiatric nurses with whom the researcher worked, proved this to be true in their experiences.

Swerdlow (1994) used participant observation in a study of 30 Puerto Rican psychiatric patients. The purpose of the study was to find out the role of ethnicity, community structure, and folk concepts of mental illness in facilitating the adaptation of long term psychiatric patients to community living. It was concluded that the folk concept of "nervios" helped to foster the integration of these patients in a wide range of community networks. Nervios was referred to as the distressing emotional states and illness phenomena. With the Puerto Rican people, Swerdlow explained that there were two concepts which were used in the meaning of mental illness. 'Nervios' and 'Locura'. In comparing the two he wrote, "locura refers to unpredictable behaviour, often without regard to self preservation. On the other hand, nervios may include such symptoms as chronic agitation, inability to concentrate, or pacing and crying, or silent brooding in its depressive manifestation" (p. 221). While 'nerves' may be treated with rest, change of scene, medication, or dieting, sufferers of 'locura' are stigmatised and

thought to require physical restraint and confinement. Similar conclusions were made by Garrison (1978) and Harwood (1977).

Swerdlow (1994) asserted that his informants, despite the 'chronic' nature of their illness, repeated hospitalisations, dependence on psychotropic medications and the inability to perform major social roles, interpreted their distress as nervios and not the much more stigmatising folk concept of 'locura'. This is consistent with the Malawian folk concepts of 'kuzungulira mutu' and 'misala'. 'Kuzungulira mutu' can be equated with 'nervios' while 'misala' is like 'locura'. 'Nervios' and 'kuzungulira mutu' are folk concepts which have a normalising and integrative function because they are indicative of conditions which can affect anyone in the community, when one experiences high levels of stress. This means that there is no qualitative distinction between the patient and the community.

Similar research findings regarding the normalising role of using the 'nervios' classification to interpret mental illness has been discussed by Jenkins (1988) in her study of 40 patients and 61 families of people affected by schizophrenia, and of Mexican-America origin, using in-depth interviews. She concluded that in invoking a condition that in its milder forms is normal and within the range of the socially acceptable, the difference between the patient and the rest of the family are minimised. In the descriptions of 'nervios' she reported that some members of the patients' families said they also suffered from this problem, although in milder forms. Jenkins argued that this perspective serves to reinforce and affirm family bonds by casting the ill person as one just like them.

The research studies cited have shown that implicit in folk concepts of mental illness is a theory of causation, an explanation of how the illness functions, beliefs about

sick role expectations and a particular meaning which is ascribed to the illness (Kleinman, 1973, 1980). Each of the above studies indicated that the meaning of illness is cultural-specific and each culture should be studied to identify the meaning of illness in that particular context so that effective nursing care which is culturally appropriate will be offered. For the above mentioned reasons a description of mental illness is particularly relevant to Malawi.

Cultural Explanatory Models: Aetiology of Mental Illness

Apart from the cultural-specific definitions of mental illness, common explanatory models for the aetiology of psychiatric disorders has also been found to play a big part in the meaning of the illness (Wittkower & Dubreuil, 1973). They have been helpful in the integration, reinforcement and affirmation of family bonds. Kuo and Hopkins-Kavanagh (1994) argued that every society has explanatory models, which are "...sets of ideals about aetiology, process, signs and symptoms, meaning, treatment and prognosis of the illness" (p. 553). Common explanatory models include heredity, punishment by the gods or ancestors for past behaviour of the family, or a reflection of poor guidance and discipline of a family leader (Shyu, 1989).

In most African countries, Malawi inclusive, illness in general and mental illness in particular is believed to be a result of angry gods (chauta) who punish wrongdoers. For example, those who violate taboos, ancestors and other spirits who feel they have been too soon forgotten or otherwise not recognised or purified by offerings (nsembe) may be punished. Bewitchment is another cause of illness. Others attribute mental illness to spiritual possession, loss of basic body equilibrium usually by the entry of excessive heat or cold (mphepo ndi madzi), and the 'evil eye' (tsoka). Aggression or

punishment is directed against a single person as a result of the will and power of another human being or supernatural agent or being (Wilkinson, 1991, 1992).

Spiritual possession is believed to be the cause of mental illness in the South African countries. Quupe (1990) conducted a study to find out factors which contributed to the cause of mental illness in a Johannasberg hospital, South Africa using 100 males and 75 females. Ninety-eight percent of the participants associated their illness to 'Mafufunyane', spiritual possession. In this culture, witchcraft was not viewed as a cause of mental illness, unlike in the Central African cultures. Quupe recommended that further research be carried out on the mental health personnel's perspective, in order to compare their beliefs and those of the patients, so that culturally appropriate care is rendered.

In the Chinese culture, on the other hand, there is belief that interrelationships between psychological and physiological functions of persons who are mentally well are integral (Lin, 1981; Lin, 1983). Kleinman (1980) defined 'neurasthenia', which is a term that many Chinese use as a condition characterised by headaches, lack of energy, weakness insomnia, and dizziness. The Chinese are oriented towards frameworks of understanding that physical illnesses are related to emotional upheaval, poor relationships, and psychosomatic illnesses (Kuo & Hopkins-Kavanagh, 1994). They attribute such conditions to 'elevated liver fire', 'insufficiency of the kidney power', or 'an exercised heart' (Cheng-Louie, 1981). In Taiwan they have a term, 'shen-ching-shuaj' which is attributed to weakness or exhaustion and is used to describe a mixture of fatigue, insomnia, headache, and poor concentration. Tseng and Wu (1985) contended that somatization allows displacement of psychic conflicts that in themselves are not acceptable, and therefore, reduces stigma of mental illness and fosters hope for

treatment. Such conceptualisation also removes fears of chronicity and permanence of mental illness and reduces anxiety about the future as well as reinforces adaptive social behaviour (Hsu, 1974).

Different cultures have different expectations of the mentally ill and they associate mental illness with different kinds of behaviours. Katz et al (1988) studied the expression of psychosis in Indian and Nigerian cultures. They interviewed 1,379 relatives of people with schizophrenia from the two settings. The result indicated differences in the experiences which were related to societal expectations. The experiences of the Indian patients included fear of losing control of self, experiencing strange sensations in the body, social isolation, attention seeking, and egocentric behaviours. On the other hand, the Nigerian participants experienced hypercriticism of the self, responsibility and independence. The researchers concluded that culture influenced the experience of mental illness, and recommended further research on the topic.

Why Explore the Human Experience of Mental Illness?

Illness and disease are facts of everyday life. Nevertheless, personal experience of illness can have an unexpected impact, physically, psychologically and socially. People attribute meanings to illness and its impact which may be interpreted differently by health professionals, creating misunderstandings (Frankl, 1962; Lomas, 1967). These misinterpretations of illness experience can result in unsatisfactory and fragmented care, noncompliance with treatment, lack of control by sufferers, and incomplete information-giving by health-care providers (Brooker & White, 1993; Montbriand & Laing, 1991). Mental illness experience has never been fully explored, so misunderstandings could be wide spread.

Research on the human experience of mental illness in Malawi has been extremely limited as in most African countries (Ben-Tovim, 1987; Mbuluma, 1990; Wilkinson, 1991). Ben-Tovim (1987) attributed this to the fact that misconceptions have been perpetuated that patients' judgements and opinions are drastically affected by their illness and that their experiences are not worthy of consideration. This notion has been disputed by some theorists, for example those who argue that all human beings have an innate drive towards competence (Frankl, 1962; 1992; Hatfield, 1989). It is because of this drive that human beings strive to survive both physically and psychologically. Human beings either attempt to adapt to their environment or change it (Coward, 1987). Several studies on patients' accounts of their experiences reveal an active process of the struggle to cope and adapt to mental illness. Their descriptions of the experiences have provided very valuable information. Speedy (1993) asserted that to provide a better understanding of a situation, it is important to analyse the meaning from the perspective of the person experiencing the situation. Similarly, Steeves and Kahn (1986) contended that as individuals are unique, so too are the meanings they create in relation to a situation. Elwell and Gillespie (1995) argued that the care they received as mentally ill persons was not adequate and appropriate because nurses did not understand the needs of the mentally ill persons. Similar complaints were narrated by other authors such as Davis and Cannava (1995), Hicks (1989), Phillips (1993), and Turale (1994).

Turale (1994) conducted a study of 15 Koories in the city of Ballarat, Australia to find out their perceptions of mental illness. She used a phenomenological approach over three months to collect data. The respondents in the study complained about their experiences in the health care system as their voices were not being heard. Other

people's recommendations were being imposed on them. She contended that interventions were ineffective because they were drawn from the experiences of the health care professionals and not from the persons living the experience.

Hicks (1989) found that patients did not perceive that mental health professionals had an understanding of the problems and needs in their lives. Such comments make it necessary for health care professionals to take up research using an interpretive paradigm where patients are able to describe their experiences.

There are a few studies on the experiences of the mentally ill persons. However, most of these studies have concentrated on patients with schizophrenia, have been conducted in other settings, and were not in Malawi. Selected research studies related to mental illness will be reviewed in terms of the psychological, social, physiological and gender issues, suffering as interpreted by caregivers, and coping strategies of the ill persons.

Social Issues

A number of negative responses to people with mental illness have been discussed in studies reported in the literature. People with mental illness experienced negative reactions (Vellenga & Christenson, 1994) and a variety of psychological distress including feelings of being ashamed, feelings of being lonely, depression, and loss of self respect (Saris, 1995).

Social distance and stigma have also been ranked as the most stressful event during community living experienced by many mentally ill individuals (Hicks, 1989). Patients have reported feeling conspicuous, out of place and not understood by other people. Such feelings resulted in isolation and nonbelonging (Brydolf & Segesten, 1995).

An anonymous author (1989) in an American publication, described several experiences of mental illness. Stigma was described as the biggest problem, and its associated feelings of shame, humiliation, rejection, and confusion leading to not wanting others to learn of the mental illness. Further explanations about the ambivalence, uncertainty and hopelessness which is magnified by the illness, and the resultant grief for the loss of the normal self and dreams which could not be fulfilled were given. Unlike most mentally ill persons, this author described hope of getting well because of social support and networking, the spiritual involvements and positive thinking.

Similar descriptions of the experience as a mentally ill person were given by another anonymous author (1993). This author commented that a personal story may help other people to understand what a mentally ill patient faces and perhaps help change the way staff interact and treat the patients. It was contended that there is still strong stigma attached to mental illness and believed that psychiatric nurses reinforce that stigma. This anonymous author further explained that life in the prediagnostic phase was better than the label of mental illness, and stated, "being in the closet" (p. 17), was better than having a label of mental illness. The two anonymous authors described similar experiences of stigma and feelings of being shunned by people. Although these are descriptions from the mentally ill individuals who volunteered to document their own feelings, they are congruent with other research reports.

Vellenga and Christenson (1994) used the phenomenological method to explore the lived experiences of 15 mentally ill clients in an out-patients clinic of the upper midwestern United States of America (USA). Four themes emerged from their analysis of patients' descriptions. These were stigmatisation and resulting alienation, loss, a

pervasive feeling of distress, and acceptance. They concluded that first person accounts helped in identifying concepts that best capture and name the personal perceptions of the severely and persistently mentally ill persons. Such perceptions could be used in therapeutic relationships and the themes incorporated into treatment plans for the mentally ill. Again, the respondents reported that mental illness was associated with stigma which is the origin of many problems faced by mentally ill persons.

DeNiro (1995) used content analysis to identify the experiences of alienation with 20 persons who were diagnosed with schizophrenia in the USA. Similar to the themes of Vellenga and Christenson (1994), DeNiro came up with themes such as, loneliness, social isolation, lack of solidarity, and feelings of nonbelonging. In this study of alienation in residual schizophrenia, DeNiro (1995) reported that the 20 subjects believed that they were treated as people to be avoided. Statements like, "people react to me somewhat negatively"; "If you have got mental illness behind you, there is no trust", and "People will honour a physically disabled person before they honour a mentally disabled person" (p.192), were made by DeNiro's participants. In conclusion, she asserted that first person accounts form a foundation for exploring interventions which might work more effectively with individuals with schizophrenia.

Joseph-Kinzelman, Taylor, Rubin, Ossa, and Risner (1994) conducted in-depth interviews with 15 selected discharged mentally ill persons in midwest USA to find out their perceptions of being hospitalised. In the descriptions of their experiences, the issue of stigma as in the other research findings, was the most significant theme. They made statements like, "people watch you and stay away", and "can't talk about mental illness like physical illness. It's like I am contagious" (p. 30). In this study, the most

significant finding was that the mentally ill person could articulate different feelings and was able to describe corresponding helpful experiences.

Recently, Elwell and Gillespie (1995) in their illness narrative, described the personal experience of mental illness as lived by themselves as women in Tasmania, Australia. They described it as a dead loss, evil, a lack of control of oneself, fear of bizarre behaviour, and of not being wanted by family and friends. They also described the stigma of being mentally ill. Stigma which is attached to mental illness has greatly affected the mentally ill persons so much so that their abilities for recovery, the treatment programs they undergo and the support they receive is not adequate to enjoy normal life as other citizens in the communities (Elwell & Gillespie, 1995).

The studies described above, though conducted in different settings, derived similar findings. The most significant finding is that of stigma and it's resultant alienation and social distance. Even though cultural-specific definitions and cultural explanatory models of aetiology of mental illness are said to reduce the stigma which is attached to mental illness, research studies to support the notion were not found. Stigma, which is a mark or sign of shame, disgrace or disapproval of being shunned or rejected by others (National Mental Health Strategy, Australia, 1996), is still a reality for many mentally ill persons. Some of the respondents commented that the stigma was reinforced by the caregivers, especially nurses. The reason given was that nurses did not seem to understand the needs and meanings the patients associated with their illness. It is therefore, of prime importance to study experiences and meanings attached to illnesses, in this case, schizophrenia and bipolar affective disorders.

Psychological Issues

People with mental illness experience a grossly distorted reality (Anscombe, 1987). They suffer high levels of stress and anxiety as they struggle to negotiate between the world as others know it and the world of their inner reality (Hatfield, 1989). Freedman and Madison (1974) at the University of Wisconsin examined 60 autobiographical books written by people with schizophrenia for descriptions of psychological changes. The patients' descriptions included perceptual and cognitive experiences. The most commonly mentioned perceptual changes included both increased and decreased sensory disturbances. The cognitive experiences included attention deficits, increased associations of ideas, mental exhaustion, memory deficits, and problems with comprehension. The authors concluded that such subjective experiences provided a glimpse into the inner world of people with schizophrenia and helped in making a "differential diagnosis between schizophrenia and other pathological disorders" (p. 339). The descriptions, though written by mentally ill individuals who could articulate their experiences at a higher level, are congruent with narratives from other studies.

More recently, Hatfield (1989) studied four schizophrenic and deinstitutionalised chronically mentally ill persons in Maryland, USA. In-depth interviews were used to identify essential components of the lived experiences, especially their accounts of stress and coping with schizophrenia. After analysing the descriptions, the themes which emerged were; altered perceptions, cognitive confusion, attention deficit, and impaired identity. The respondents in this study described many methods that they used to cope with dilemmas, insecurities, and limitations which were caused by mental illness. Hatfield concluded that to accurately explain each individual's behaviour and to

respond empathically, clinicians need to learn more about the inner world of the patients, because first person accounts are rich sources for learning about their experiences.

Another recent research study which reports psychological issues of mental illness is the one by Baier (1995). Baier interviewed six persons with schizophrenia and five family members to identify descriptions of living with schizophrenia and any uncertainties associated with the illness. Using content analysis, Baier elicited definitions of uncertainty including affective responses of fear, worry, and hope. Some of her respondents expressed optimistic feelings about the future as mentally ill persons. Others described varying degrees of being threatened by the future. She concluded that persons with schizophrenia can provide a rational report of their experiences and thoughts and also that valuable information could be obtained by talking with persons experiencing schizophrenia to learn more about their experiences.

Saris (1995) conducted an ethnographic study to elicit a story of chronic illness from a schizophrenic person in the Netherlands. His informant articulated a rich description of emotions such as abandonment, terror, amusement, suspicion and hostility. The informant explained how it felt to be socially marginal or how it felt to realise that his reality was slipping away. The injustices which he experienced because people saw the schizophrenic as the most lowly person compared to other marginalised people such as those with manic depression and alcoholism, were described. Descriptions of hopelessness, powerlessness and voicelessness were also given by Saris' informant. The informant indicated that mental illness was a suffering, and the treatment which he received did not make it any easier. He talked of the side effects of the drugs which interfered with body movement and some activities such as involuntary

muscle movements, impotence, and loss of speech. Saris concluded that the narratives exposed silences and provided a rich source of information which could be used to limit discourse in managing mentally ill persons and also provide a theoretical basis for further research. This study reports almost similar descriptions to DeNiro (1995) and Vellenga and Christenson (1994) even though methodologically different.

Suffering; A Caregivers' Interpretation of Mental Illness

Suffering has been defined as physical and/ or psychological suffering (Mason, 1981; Oberst, 1978). Psychological suffering is defined as an individual's experience of threat to self and mental pain. (Kahn & Steeves, 1986). Psychological suffering is another term which has been related to a mental illness description (Davis, 1981). There are many research study reports from persons experiencing such suffering. Although the word suffering in not made explicit in the titles, suffering has been discussed. Several research studies, however, have described suffering as perceived by caregivers (Badger, 1996; Fadden, Bebbington & Kuipers, 1987; Mason, 1981). Saris' (1995) respondent simply mentioned that mental illness means suffering, and the issue was not pursued further.

Davitz and Davitz (1981) studied 22 nurses from six different cultures in America using structured interviews. They found that there were variations in these nurses' inferences of patients' pain and suffering which were related to the nurses' culture and socio-economic backgrounds. They concluded that the presence of an implicit belief system affected meanings of experiences. The participants in this study described suffering as an experience of individual self, and that it was related to the 'self' that suffers.

Badger (1996) using a purposeful sample of 11 English-speaking family members who were living with a member with manic-depression, conducted in-depth interviews to find out their lived experiences. The respondents' descriptions included such experiences as suffering, living two lives, searching for reasons and solutions, fighting the battle and seeking social support. It was concluded that the findings provided a basis for understanding the experience of depression from the perspectives of the caregiver.

Even though in the studies cited above there was mention of mental illness and suffering, the relationship between the two was not made explicit. The respondents who made reference to the concepts of mental illness and suffering were not mentally ill persons and so the boundaries between the concepts remained blurred.

Physiological Issues

Most mentally ill individuals experience side effects from psychotropic medications. Most of these side effects cause physiological changes because the medication is taken for prolonged periods (Stuart & Sundeen, 1995). Most of the side effects described were those that interfere with involuntary muscle movements (Joseph-Kinzelman et al., 1994). Some mentally ill individuals have actually complained that their lives are controlled by drugs, and these drugs interfere with their normal selves (Saris, 1995). Others believe that medications decrease their feelings of personal confidence. For example, one of DeNiro's (1995) respondents said, "I felt nervous, more tensed up,..., about meds, off meds I am more sure of myself". Another respondent in the same study stated, "I talk less when I am on medication, and it doesn't let me be me". Side effects of some medications such as tremors, drooling of saliva and torticollis increase isolation for some patients. There are many studies done on side

effects of psychotropic drugs (Hartigan del Campo, Carr & Correa, 1983; Hitchens, 1977; Van Putten, 1974), but none on the experiences of persons taking the drugs. Respondents in other studies just make a few comments on the physiological experiences related to medications for mental illness.

Gender Issues Related to the Experiences

There was limited literature on the differences in the experiences of mental illness between men and women. There are more men who suffer from schizophrenia than women, and more women suffer from manic depressive disorders (Steen, 1996), but the differences in their experiences is unknown. The reason could be that women have not been represented in research or that women's experiences have not been the focus of research even when the topic was related to women (Chrisler and Howard, 1992). In some research the method of reporting using the masculine pronouns made it difficult to be sure women were also represented (Russo, 1990). Beverley, Douglas, and Hughes (1990) argued that there is no evidence that gender is associated with mental illness. In the study of staying well for the newly discharged mentally ill Beverley et al. used a convenience sample of 100 newly discharged mentally ill persons in Canada. A questionnaire was sent to the participants as a tool of colleting data for the quantitative study. The results of the study indicated no significant difference in the experiences between the genders. The authors recommended further research on personal supports such as the family and gender issues related to the experience of mental illness.

Even though there is limited literature on gender issues regarding the differences in their experiences, it is worthwhile here to mention that a few authors have studied gender issues. For example, a study on women and depression in the USA, Jack (1991) asserted that cultural norm values placed on males and the patriarchal views of life

lower women's self esteem as they measure themselves against the norm. Such beliefs cause more depression in women. It is also believed that for women, interpersonal needs are more important to them than for men, therefore, women are affected more if society shuns them, and the effects of stigma are more pronounced in women than in men (DeNiro, 1995; Saris, 1995). There were no other reports with which to compare the results of this study, but other articles do report different reactions to illness according to gender.

Steen (1996) explained that some male norm characteristics are self sufficiency and independence. Such characteristics can affect the male mentally ill person because of the effect of his illness means that he needs to depend on others. Instead he may become homeless, since society expects him to be independent.

Flaskerud (1986) conducted a quantitative study to find out the profile of chronically mentally ill patients from four community mental health settings in North America. She systematically sampled 160 mentally ill homeless individuals and found that 63.3% were males, unmarried, divorced or separated. Flaskerud described the chronically mentally ill homeless as largely male and unmarried, and reported that males were unwilling to use the traditional support system. The profile showed deficits in interpersonal relationships which made it hard for the patients to cope with their illness. In that study, the researcher provided limited comments on the gender issue. There is a possible need for more research regarding gender issues in mental illness.

Strategies Used to Cope with the Experience

Even though there are limited studies reporting the differences in the experiences between men and women, there are a few study reports indicating that the coping strategies are different for each gender. Frederick and Cotanch (1995) used a

convenience sample of 33 adult outpatients with schizophrenia using in-depth interviews to elicit self-help strategies they used to cope with auditory hallucinations. They found that men used techniques that were more isolative, and women used more interpersonal techniques. The researchers recommended further research on the gender differences in coping with the experience of mental illness.

There might be differences in the coping strategies, but both men and women find means of coping with the experiences of mental illness (Solokove & Trimble, 1986). Garrison (1978), Sokolovsky (1978), and Trimble (1981) suggested that chronic mentally ill persons do not lead solitary, isolated lives as most people believe. They have their own unique social networks that offer them social support and reduce stress and stigma. The social support ranges from the religious and spiritual activities and beliefs (Laing, 1994), to the family and significant other including belonging and the need to belong (Reinhard, 1994; Wilkinson, 1992).

Other methods of coping with mental illness described by Saris' (1995) respondent was active participation in treatment programs, trusting instincts and having self control, acting as his own agent in his care, and cultivating the self, because he felt he had lost the normal self. Assuming such an attitude, it is probable that this means that the individual has accepted his condition. Vellenga and Christenson (1994) described acceptance as a coping strategy in mental illness because once an individual accepts the illness, a start is made in looking for ways of living with the condition.

An anonymous author (1989) described spiritual involvement, hope, and positive thinking as means of coping with mental illness. Leisure and church-related activities were rated as the most important community support systems in Beverley et al.'s (1990)

study of factors which contributed to staying well in the community following discharge from a mental institution.

Summary

The studies reviewed demonstrate a variety of factors which may shape a person's experience of mental illness. Elements of experience frequently described can be categorised as social, physiological, psychological and gender issues. Coping strategies were also reviewed. Under each category, several elements were discussed. For example, stigma and its resultant alienation, social isolation, and loss were discussed under social issues. Alterations in perception and cognition have been found to be the main psychological problems. The side effects of psychotropic medications which result in interference with involuntary muscle movements affecting the individuals were the physiological elements which were described by many participants in the studies.

Cultural issues were also reviewed because experiences are better understood within a context where they occur (Kleinman, 1973,1980). Culturally appropriate care can only be provided if each culture is studied to understand the meanings attributed to illness in that particular society. It is also believed that first person accounts of lived experience are a rich source of information (Baier,1995; DeNiro, 1995; Freedman & Madison, 1974; Hatfield, 1989). However, no studies on the experience of mental illness have been carried out that reflect the Malawian experience. Absence of such data highlights the importance of this study. It will add to the knowledge base regarding the experience of the mentally ill schizophrenic and bipolar affective disorder patients from a Malawian perspective.

CHAPTER THREE

Theoretical Framework

The framework underpinning this research is Parse's (1981, 1987, 1992) theory of human becoming. This framework has been chosen in conformity to recent theorists and researchers who propose that nursing science should confront the philosophical enigma of the meaning of meanings (Cody, 1994). Dossey (1991) and Siegel (1989) asserted that thoughts, images, and beliefs do heal the body and called for greater attention to meanings of illness. Achiterberg (1990) and Smolan, Moffart and Naythons (1990) further asserted that interpretation of the meaning of one's relation with the universe has been associated with healing. It is therefore essential that nursing's propositions about meaning should provide a framework for understanding life as it is humanly lived and for performing the art of nursing (Cody, 1994). Parse (1981, 1992) assigns to meaning a central place in her human becoming theory.

There are three major themes which emerge from the assumptions underpinning Parse's theory. These include; meaning, rhythmicity, and cotranscendence. From these themes, three principles were generated. Firstly, human beings in interrelationships with the universe cocreate meanings at many different levels. Human patterns reflect lived choices as individuals move towards cherished hopes and dreams in the process of becoming. It further explains that human beings reveal value priorities in the meanings given to life situations (Mitchell, 1990). Thus, the meaning individuals with mental illness assign to the lived experience of mental illness uncovers what is valued by them. From this perspective, these individuals with mental illness cocreate with significant others the meaning of their experience and choose ways of being, regardless of their

situation. The meaning given to the situation is reflected in the individual's patterns of living value priorities, which is health (Parse, 1981).

Parse's second principle describes the unity of the human being's rhythmical patterns of interrelating with the world. The unity of rhythmical patterns of relating is revealed in the human being's living both sides of a rhythm, although one side may be predominant over the other at any given moment in time (Parse, 1981, 1987). With the mentally ill, the theme of rhythmicity is reflected in the individual's way of revealing and concealing the experience, while connecting and separating amidst the opportunities and limitations of mental illness.

Parse's third principle, cotranscendence, describes the process of mobilizing and creative ways of moving beyond the now moment towards unfolding possible ways of living. Moving beyond the moment is connected with emerging fears, insecurities, concerns, hopes, and value priorities in changing views of living with a chronic problem such as mental illness. According to Parse, Coyne and Smith (1985) and Parse (1981), health means an open process of becoming, unfolding towards greater openings. Parse (1981, 1987, and 1992) further describes health as an expression of values at the moment and as a way of living a personal commitment . In this view, the individual with mental illness is living intentionally, struggling to move beyond with valued ways living with mental illness. Thus, Parse's theory of becoming provides a perspective on living with mental illness.

This theoretical framework can be used to analyse knowledge about the meaning of existence for the mentally ill. It has been chosen because it provides a link between the study findings and theoretical knowledge. The nurse's knowledge and understanding of meaning of mental illness and human existence provide a basis for

improved guidance and appropriate interventions in caring for the mentally ill. This will enable the mentally ill persons to find meanings in their existence when they have a feeling of emptiness or they think there is no life after mental illness (Frankl, 1992).

CHAPTER FOUR

Methodology

Introduction

Originally a phenomenological method was to be used to explore the experiences of living with mental illness, but after data collection, and on review of the data, it was decided to change the method of analysis to descriptive content analysis. The reason for the change was that the respondents were reluctant to talk and describe their lived experiences. While investigating the experience, sensitivity to the culture of non disclosure was considered paramount. Otherwise the nurse/patient relationship would most likely be jeopardised. People in Malawi find self disclosure beyond a superficial level very difficult. They have trouble putting mental illness into words, or are embarrassed or feel ashamed (Wilkinson, 1992). Even though the respondents were able to describe their experiences , the in-depth nature of the data obtained was not realistically achieved to the satisfaction of the researcher. Therefore, using the intended method of analysis was not suitable.

Both the phenomenological and descriptive analysis methods belong to the same qualitative research paradigm (Robertson, 1994). This paradigm focuses on the reality of human science (Munhall, 1994). Descriptive content analysis is the first level of analysing data which aims to explore, analyse and describe particular phenomena directly and freely from unexamined presuppositions. The phenomenological approach, however, focuses on the process of exploring through the data (Keen, 1975; Munhall & Oiler, 1986; Omery, 1983). Common themes and essences are searched and established to form patterns of relationships shared by particular phenomena (Porter, 1994; Streubert & Carpenter, 1995).

The Design

The study was designed to describe the lived experience of mental illness of selected adult individuals in Zomba, Malawi, by exploring, analysing and describing a phenomena from the individual's narrative. A qualitative design within the interpretive paradigm was selected to describe the experience of mental illness in this study. A descriptive content analysis method was used. Descriptive methods are recommended for research when little is known about a topic and to understand or describe a phenomenon (Burns & Grove, 1987; Knafl & Howard, 1984). It is a fundamental research design from which a better understanding can be gained of the relationship between individuals, behaviours, or events as they occur (Barnard, 1981). Such understanding is gained by descriptions of the experiences from the persons living the experience or situations (Parse, 1987).

Content analysis "is a method of data analysis which is concerned with meanings, intentions, consequences, and content" (Downe-Wamboldt, 1992, p. 314). This method of data analysis acknowledges an experience from the perspective of the person and connects the experience to a situation in the person's life (Iwasiw & Olson, 1995). Content analysis is a recognised method of data analysis for the first level of qualitative research studies and in recent years, it has been used by some researchers to describe the human experiences of phenomena (Baier, 1995; DeNiro, 1995; Iwasiw & Olson, 1995).

Participant Selection

Only a small number of participants are required in qualitative research because it permits the deep case-oriented analysis and maximum understanding of the diversity of the phenomena (Sandelowski, 1995). A purposive sample of 10 participants was

used. Purposive sampling is the most common method used in qualitative studies in order to access selected participants who can provide a rich descriptive data base (Streubert & Carpenter, 1995). The sample comprised six women and four men. All the participants were of Malawian origin. This was done in order to exclude other nationals such as refugees from other parts of Africa who now reside in the country. The participants had been diagnosed mentally ill between 5 to 10 years ago. All lived in Zomba, with either their families or alone. However, each remained under the care of the community mental health team. The criteria for inclusion in the study were persons who were (a) Malawian permanent residents, (b) aged between 25 and 45, (c) diagnosed as mentally ill 5-10 years ago, (d) living in Zomba and attending the community mental health service, (e) able to articulate his/her experiences, and (f) not psychotic at time of interview.

Procedure

Permission to undertake this study was sought from the Higher Degrees and Ethics Committees at Edith Cowan University. Once granted, it was also necessary to obtain permission from the Ministry of Health Research Department in Malawi as access to records was sought from a government run hospital, the Zomba Mental Hospital. Both Ethics Committee of Edith Cowan University, Australia and Ministry of Health Research Department, Malawi gave permission for conducting this study (Appendix A). The Principle Nursing Officer (PNO) of Zomba Mental Hospital was contacted by the researcher to gain access to the targeted population. The administrative head of the Zomba Mental Hospital is the PNO and is the leader of the community mental health team members.

The researcher attended the community mental health clinic of the Zomba Mental Hospital at the time of the patients' routine visits to outreach clinics. The outreach clinics which were visited were, Thondwe, Namadzi, Magomero, Namasalima, and Namsadi. This was to inform potential participants of the intended study. Information on the purpose of the study, benefits of the study and time estimates of interviews were communicated to them. Potential participants were also informed that interviews were to be audiotaped. This was done to confirm their willingness to participate in the study and to obtain verbal consent. Names and addresses of the participants who were willing to participate in the study were noted and appointments to meet them at their homes where interviews were to take place, were arranged. Eleven patients volunteered to take part in the study (Appendix A).

During the interviews, audiotapes, observations by the researcher and fieldnotes were used as data collection tools. By using a combination of observation, interviewing and notetaking, the researcher was able to use the different data sources to validate and cross check findings (Patton, 1990). Fieldnote taking, interviewing, audiotaping and observation are well known methods of data collection. These methods were chosen because of their combined strength (Breitmayer, Ayres & Knafl, 1993) and to ensure credibility of the data.

Data Collection

The interviews were conducted in the Chichewa language at the homes of the research participants at a time convenient to them. The first interview, which lasted 10-15 minutes, was used to establish rapport, obtain written consent and demographic data (Appendix B). During this interview, the purpose of the study, method of data collection including audiotaping, estimated time involvement, and benefits of the study

were repeated to the participants. Willingness to participate in the study was reconfirmed after which the consent forms were signed. The participants were informed that participation was voluntary, and that they could withdraw from the study at any time and their care would not be jeopardised in any way. However, none of the participants withdrew. One of the participants was, however, withdrawn from the study after the initial interview because she could not articulate any of her experiences appropriately and she was in a psychotic state. A total number of 10 people were included in the study. Even though it was a formal interview, the setting was informal: on the veranda, in some instances under a tree, and at other homes, in the lounge rooms. Each participant was able to articulate personal experiences, easily engage in social conversation, were humorous, affable, and eager to cooperate, but disclosure in depth was difficult. The interviews lasted between 10-15 minutes. Arrangement was made for a follow up interview a day or two later.

Each second interview lasted between 50 and 90 minutes. To make the environment conducive for story telling, and since the topic under discussion is taboo in Malawi, privacy was maintained by not allowing other people around within hearing range. Interviews were unstructured, and the researcher acted as a research tool (Seidman, 1991), using a question guide comprising open-ended questions and prompts (Appendix B). This is consistent with qualitative methods of research (Morse, 1991; Thorne, 1991). The following question was asked after the initial greetings: 'Please describe your experiences since you were diagnosed as being mentally ill'. The participants were asked to describe their thoughts, perceptions, and behaviours that they could remember since they were diagnosed. It was initially difficult for the participants to start describing their experiences, therefore, the researcher used other open-ended

questions like, 'tell me, how does it feel to be mentally ill', 'can you share with me some of the thoughts which have occurred to you since you were diagnosed mentally ill', while at the same time respecting the culture of non-disclosure. After much probing, the participants were able to narrate their experiences.

Each interview was audiotaped and transcribed verbatim in Chichewa language by a paid transcriber using a typewriter. The researcher randomly selected three samples of the transcriptions and crosschecked with the audiotapes for accuracy of the transcriptions. Each transcription was translated into English by the researcher. No problems were encountered during the translations since the interviews were conducted in the researcher's own language. Two random samples of the translations were cross-checked for accuracy with a second bilingual person who was also a health care worker in Zomba, Malawi.

Immediately after each interview, observational records were written in a diary kept by the researcher based on the interactions, non-verbal cues, and the subjective impressions of the researcher. The observations provided a cross check on what was reported during the interviews. These provided additional insights into the physical, emotional, and social environment experienced by the participants.

Data Analysis

Data analysis was done concurrently with data collection from the time of the first interview using procedures described by Streubert and Carpenter (1995). The following were the procedural steps used:

1. A personal description of the phenomenon of interest was explicated.

2. The researcher's presuppositions were bracketed. The researcher firstly 'bracketed' any values, views and knowledge about the experience of mental illness.

Bracketing is required to separate personal bias from interpretation of the interviews and observation data (Morse, 1991). This was done because the researcher has worked as a psychiatric nurse in this community, therefore the process of bracketing was very important to achieve data which truly reflected the experiences from those who lived the phenomenon of concern. Table 2 shows the researcher's assumptions.

3. After each interview the researcher listened to the audiotapes to become familiar with the data. Both the Chichewa and English versions of the transcripts were read through at the same time while listening to the audiotapes. The researcher carefully read the transcriptions from each interview to obtain a general sense of the experience. This was done many times in order to sense the meaning of the whole, to compare elements of the data and to identify areas for elaboration (Field & Morse, 1990).

4. Formalised descriptions of the phenomena were developed.

5. The participants validated descriptions of the experience and any new data was incorporated into the fundamental structure.

6. The relevant literature was reviewed. A literature review can help provide supporting evidence to the findings of the study (Walshe, 1995).

Table 2

The researcher's presuppositions about patients' experiences

Assumptions
1. The mentally ill persons can not articulate their experiences
2. Their experiences will include anger, frustration, despair
3. Mental illness is the end of life, and the respondents will talk about suicide
4. The mentally ill persons in this setting believe that they were bewitched
5. The mentally ill depend on their families to support them financially, they are not resourceful and they lack initiative

The initial phase of the analytical process was sorting and coding interviews from the handwritten data (Munhall & Oiler, 1986). Codes were developed from the data to represent common and unique information. Significant statements were also extracted from the data and grouped into categories. The definitions of each category were written on separate sheets of paper and attached to a large table top. The transcripts were read and re-read and data segments were cut and pasted onto the appropriate category code. Subsequent episodes were analysed to determine their fit into existing categories, and new categories were developed as needed. Similar categories were collapsed into topics paying attention to the balance between the reduction of categories and the maintenance of detail sufficient to fulfil the descriptive purpose of the study. Initially, codes were grouped into categories which were later reduced and modified (Glaser & Strauss, 1967; Holsti, 1969; Krippendorff, 1980) and higher order categories were differentiated using Parse's theory of Human Becoming using creative conceptualisation at the second level of abstraction (Parse,1992).

Confirmability of Qualitative Data

Techniques for determining reliability and validity in qualitative research have been discussed by several researchers (Beck, 1993; Kahn, 1992; Miles & Huberman, 1984; Sandelowski, 1986). In this study, specific measures were taken to address credibility, fittingness, auditability, and confirmability (Sandelowski, 1986). The credibility of the researcher's interpretation of the data was enhanced by the participants' validations. Four of the participants were asked to provide confirmation that the descriptions which the researcher had discussed were representative of what they had described as their experiences. This was done in order to enhance validity as suggested by Guba and Lincoln (1981) as a validity check.

Auditability is suggested as a criterion for evaluating the consistency of qualitative findings (Beck, 1993; Sandelowski, 1986). Auditability is demonstrated when the researcher's decision trail can be followed, and similar conclusion reached. In this study, auditability has been attempted by the researcher, describing each stage of the research process, explaining what was done and justifying why. An independent researcher was also asked to read and analyse two randomly selected transcripts which were compared to those identified by the researcher and similar categories were identified. During data collection, the researcher used tape recording together with observation, LeCompte and Goetz (1982) also suggested that tape-recordings enhanced auditability.

Fittingness means that the study findings can be applied in contexts outside the current research study situation and are viewed as meaningful (Beck, 1993). Fittingness of the study is increased by seeking out participants who are not only living the experience under study, but those who can also articulate their experiences. In this

study all the participants were able to articulate their experiences, though at a superficial level. The researcher analysed the data line by line and excepts from the data were provided to allow the opportunity for assessment by the participants and the reader.

Confirmability was specifically addressed throughout the analysis process by use of interview summaries and independent reflections of data. An independent researcher was asked to analyse two randomly selected transcripts and tapes. The descriptions which this researcher arrived at were compared to those of the independent researcher. This was done to enhance confirmability.

Limitations of the Study

As the participants in this study were from a specific mentally ill group, the results are not generalisable outside this sample. People in Malawi in general find self disclosure difficult, and to talk about mental illness is even more difficult for this community. They have trouble putting it into words, or feel embarrassed or ashamed to speak about their illness (Wilkinson, 1992). Therefore, to ask them to tell a story or narrate their experiences was a culturally arduous task. Much encouragement ensured their description of their experiences of being mentally ill and what it meant to them. The interviews were conducted in Chichewa language then translated into English. The language difference may have caused limitations of data coding and analysis and some themes may have been lost.

Ethical Considerations

Permission to conduct research and collect data in Zomba, Malawi, was granted by the Secretary For Health in the Ministry of Health and Population, Lilongwe, Malawi. A written communication in Chichewa, the national language in Malawi, describing and explaining the study purposes, extent of participation required, the right

to cease participation at any time as well as an invitation to participate, was made available to many individuals with mental illness living in the community and attending community mental health services in Zomba. The letter was read to the participants and it was explained that interviews would be audiotaped before they signed a consent form and before dates for the interviews were set. Participants were told that no names or other identifying characteristics would be used and that information would be gathered through personal, unstructured interviews with the use of an interview guide. Participation was voluntary and participants were informed that they could withdraw from the study at any time without jeopardising their care. Each participant had the option of being interviewed in Chichewa or English. All chose Chichewa. The interview guide appears in Appendix B.

CHAPTER FIVE

Findings

This chapter, which is divided into two sections, provides a description of the findings of the research. The first section provides a description of the demographic data and the second comprises descriptions of mental illness as narrated by the participants. The data are presented as descriptions of what was observed and communicated within the interview context. Direct statements or excerpts are used to illustrate the common experiences and categories, with verbatim quotes from the data. Numerical suffixes at the completion of each participant's direct quote directs the reader to the distribution of the data.

The participants expressed appreciation for the opportunity to share their experiences and perceptions of having schizophrenia or bipolar affective disorders. "Thank you very much for wanting to hear about my illness. Nobody has ever asked me to talk about my experiences this way" (8). "I should thank you for listening to my story . I think the talk has helped me a lot" (6). The participants were able to detail their perceptions of the experience of being mentally ill but only on a superficial level owing to a general cultural orientation of non disclosure and their highly stigmatising illness (Kleinman, 1980).

Description of the sample

The sample consisted of six women and four men . The mean age of the participants was 35. The participants were predominantly single (60%), though the majority of the male participants was married (75%). Ninety percent of the participants had been previously married, and 10% had never married and remained single. Consistent with the findings of Perese (1997), schizophrenia was the most commonly

identified diagnosis, with 60% of the participants being medically diagnosed as having the condition.

The majority (60%) of the participants were living with their families and the rest lived alone. Thirty percent of the participants were earning a living either by working or running a small business. Fifty percent of the participants were unemployed but had a small farm where they grew farm produce for domestic consumption. Only 10% of the participants were employed in one of the ministries. A profile of the participants is summarised in Table 3

Descriptions of Experiences

Descriptions of the experiences were categorised as follows: view of their illness, view of self, stigma and discrimination, loss, fear, gender difference, and coping strategies. Each element will be discussed separately.

View of Their Illness

The participants' descriptions of their experiences were mainly shaped by their cultural orientation. This was evident in their definitions of mental illness, which the majority called 'kuzungulira mutu'. The cause of their illness, 'bewitchment', was evidence of the influence of their cultural beliefs. Eight of the participants defined their mental illness as 'kuzungulira mutu', a folk concept of mental illness in the Malawian context. It can be translated as 'nervous breakdown' or 'nerves'. When the participants were asked what they thought was the meaning of their illness they said "It just means I am suffering from nervous breakdown, kuzungulira mutu" (1). The other seven participants made similar comments despite their records showing a major mental illness such as schizophrenia or bipolar affective disorder.

Table 3

Characteristics of the participants

Characteristic	n	%
Sex		
Female	6	60
Male	4	40
Age (years)		
25-29	1	10
30-34	2	20
35-39	4	40
40-45	3	30
Marital status		
Married men	3	75
Married women	1	10
Divorced men	1	10
Never married women	1	10
Divorced women	4	40
Living arrangement		
Independent	4	40
With family	6	60
Employment status		
Employed	2	20
Unemployed	5	50
Self employed	3	30
Diagnosis		
Schizophrenia	6	60
Bipolar Affective	4	40

Only one participant described his illness as 'misala', which is a major form of mental illness in the Malawian culture. He said bluntly, "I am mentally ill" (10), with a tone of anger and finality. Such a description was rather unusual in this setting. This particular participant had been diagnosed with schizophrenia 10 years ago, but whether his description of his illness was related to the length of his illness is unknown.

One participant said that her illness was as a result of spiritual possession. "I was filled with the evil spirit" (8). Spiritual possession is believed to be an even lesser form of mental illness (Wilkinson, 1992). It has a different name in each of the three regions of the country. In the south of Malawi where this study took place, it is called 'Majini', in the central region, it is called 'Mizimu', and in the north, it is referred to as 'Vimbuza' (Peltzer, 1987). Spiritual possession is believed to be a very mild form of mental illness caused by stress and angry gods (Wilkinson, 1992).

This cultural-specific definition of mental illness together with a cultural explanatory mode of the cause of mental illness emerged frequently in the descriptions of the participants' experiences. Eight participants associated their illness with bewitchment, "It just means having a disorganised mind and I was bewitched" (3). The other participants made similar comments about the meaning and cause of their illness. Many of them described situations which led to their bewitchment. For example, one woman narrated "Before I got ill, we had a land dispute with our neighbours. One day I went out of the house and I found a bundle of grass tied together. I picked it up and undid it. Since that day I become confused. The traditional healer confirmed that I was bewitched" (2). Land disputes in this setting are believed to be the cause of bewitchment because Malawi depends on agriculture for its exports.

View of the Self

Change. All the participants expressed that they had experienced a change in themselves since they became mentally ill. The descriptions included change of personality, changes in the ways they related with others, and changes in their attitudes to life as a whole. Most of the participants thought that their existence seemed to be a blurred reflection, "...it is as if you are in a coma, a trance, if you compare it to physical illness" (8), and that they were nothing but a patient, a victim of an intangible illness. "I am just a chronic patient, a mentally ill patient, and nothing more" (2).

All participants commented on their change of personality, "I am a changed person now, when I am in a group I do not say anything" (7). Their descriptions indicated that they had changed from being outgoing persons to introverted individuals. They said that they had changed because other people do not respect the opinions of the mental ill persons. One woman lamented, " they do not listen to me any more" (3). Participants also expressed the feeling that they were totally changed individuals, that they did not think they were like others , "I feel that I am not like my friends any more, when I am with them, I just do not feel I am one of them. I am changed" (1). Such feelings forced most of the participants to avoid making new close relationships. This was evident in the following statement, "You see, when old friends stop coming to your place, they become distant. It is hard to make new friends. I gave up the thought of new friends" (6).

The participants made comments to indicate that they thought they had lost their independence and control of their lives. One woman said, "I just do what I am told to do. I have no control over my life since I became ill" (2). Participants also described loss of control of the self as a result of prescribed medications.

Dependence on drugs. Dependence on medication was an accepted part of the participants' lives. All the participants described the need to take medication every day of their lives. This resulted in a loss of self control because the medications ruled their lives. "I have to take tablets every day of my life to avoid a relapse. It is annoying to know that I have to depend on them, but at the same time I do not think I will be normal without them" (9). Because they have to be taken for prolonged periods of time, most medications cause severe side effects (Stuart & Sundeen, 1995). Each participant seemed to understand the importance of taking their medication but described their unhappiness with the side effects, "I am very grateful for them (medications), but it controls your life. Look at me, my hands are just shaking for no reason. I am lucky, some drool saliva all the time" (10). The descriptions of drug treatment demonstrated an inconsistency. Whilst participants were dissatisfied with the medication because of the side effects, they were also grateful for its beneficial effects and talked of the need for continued use to avoid a relapse. The embarrassing side effects of the medication caused social isolation for some participants. One of the participants said, "I cannot go out in the public like this" (5), indicating her shaking hands and distorted neck muscle, which were side effects of largactil, a psychotropic drug.

Other People's Views

The participants made a few comments about what other people thought of mentally ill persons . One man explained that before he was diagnosed as mentally ill, his family and relatives depended on him, but since he had become ill things had changed, and he explained, "People underestimate my capabilities. People think that I am a useless being, a liability. That I cannot contribute anything to the community" (9).

Another element which was identified from the participants' narration was in relation to decision making. Most of the participants pointed out that other people thought that once a person got mentally ill, decision making ability was lost. One example was the way in which mentally ill persons entered into the health care system. The families decided what was good for them. As mentally ill individuals, they had no say in anything including their own treatment. They did not participate fully in planning their care as everything was just done to them and for them, believing that it was done for their good. "My father decided to take me to the traditional healer first, then to the hospital". (8) This loss of input into treatment planning and the loss of individual control over their lives was a source of distress and worry to all the participants. One participant stated, "I am capable of doing things, but I am not given the chance, they do not trust me with anything"(6).

Some of the participants complained that their families thought they were an embarrassment, " my husband forbade me to go to social places like the church, the market place or any social gathering. I think it's because I am an embarrassment. He has never said so, but I think that is the reason" (2).

Participants also described other experiences, as well as providing descriptions of their self perceptions, views of their illness, and other people's views of their illness. Those experiences were categorised by the researcher as stigmatisation and discrimination, loss, suffering and distress, fear, gender issues, and coping strategies.

Stigmatisation and Discrimination

All participants shared feelings of suffering socio-economically from the time they were diagnosed as being schizophrenic or having bipolar affective disorder. Such feelings were categorised by the researcher as stigmatisation and discrimination.

Participants related feelings of being discredited or shamed because of their illness. Stigmatisation was described within the context of experiencing an awareness of being perceived differently. "I have been labelled 'mentally ill', this label remains with me even if I am a cured mentally ill" (6). Both the mentally ill person and the family suffer this stigma in silence. One woman lamented, "maybe because I am mentally ill and at times especially during a relapse, I do not know what I do. I might go about naked, refusing to take a shower, and making a lot of noise, I am probably an embarrassment to them. They have never said anything to my face, but I have a feeling they also suffer the same stigma as me" (3). This participant's tone of voice and her facial expressions indicated intense feelings of anger and shame for causing herself and her family such suffering.

All participants in this study expressed feelings of discrimination, of being treated differently by employers or society because of their illness. One man, who felt he had been treated differently by his employers because of his condition, said, "When I was discharged from hospital I found a letter of dismissal from the place where I used to work. I did not do anything wrong, it was just because I am mentally ill and hospitalised" (6). Many participants stated that society discriminated against them in many ways. "I do not bother much about it myself. Those people who do not want to speak to me, I don't talk to them; those who are willing to speak to me, I do likewise" (7). Another woman with similar feelings explained, "Nobody takes you seriously. When someone provokes you, you cannot report it anywhere because as a mentally ill person, you are always in the wrong. They will say it is this mentally ill person who started it all and everybody will believe that" (8).

Most of the participants felt that they had suffered some form of discrimination and stigmatisation including being shunned, laughed at, being unemployed, or silently rejected. An example of silent rejection is evident from this statement, "Even though they understand all about the suffering, I know that sitting there with them may not be acceptable. Nobody has actually told me, but one just has a feeling that the other person may not want me to get close to him or her" (2). Another woman with similar feelings said, "I am a mentally ill person, whatever I say or do, people misunderstand. They always say, what can a mentally ill individual do or say that can make any sense. Therefore, it is better for me to keep quiet" (1).

Loss

Feelings of loss emerged frequently throughout the interview and were indirectly related to stigmatisation and discrimination. All participants talked of a loss in their lives. Three major types of loss identified by the participants were loss of relationships; loss of job opportunities; and loss of personal effects.

Loss of relationships. This was the most common type of loss experienced by the participants. Lost relationships involved both platonic and intimate. Most of the female participants suffered the intimate relationship loss. One woman said, "My husband divorced me immediately I got the first episode of mental illness" (7). Another woman experiencing the loss of an intimate relationship lamented, "I am 32 years old but never married. Probably men do not want to marry a mentally ill woman" (3). In the Malawian culture a woman is expected to get married somewhere between the ages of 18 and 25 at the latest, so this particular woman felt she was running out of time for a marriage.

Loss of platonic relationships was experienced by many participants in this study. One man said, " I have experienced many problems since I was diagnosed mentally ill. For example, the people I used to associate with no longer want anything to do with me. I do not have friends any more" (10). One woman said, "I do not have as many friends as I used to before I got ill" (1). Another man said, "the other people in the community are not my friends, I greet them, they greet me back, that's all" (6).

Loss of personal effects. All of the participants in this study had been admitted to a mental hospital at some time during the course of their illness. One of the losses which they incurred was loss of personal effects from their homes during the time that they were in the hospital. One participant said, "I lost most of the things I had, my furniture, clothes, and books" (8). One woman explained that she owned livestock on her farm but had lost a few herds, "When I was in hospital, my uncle came to my house and he took some herds of cattle and sold them. I did not authorise the sale, and I never got the money" (5).

Loss of job opportunities. This kind of loss in the lives of the mentally ill was revealed by many participants. One man stated, "I never did anything wrong, and yet I was laid off" (4), while a woman said, "I have been looking for a job for a long time now, but nothing materialises. Who can trust and employ a mentally ill person?" (8). Suffering and distress were a consequence of this loss because they were unable to provide their families with basic needs.

Suffering and Distress

The overwhelming feature of the description of the experience of both schizophrenia and bipolar affective disorder was that of suffering. This experience of suffering permeated the participants' descriptions and had a major influence over their

current lives. Pervasive feelings of distress were also acknowledged. "I have had terrible suffering for over 10 years"(9). The symptoms of mental illness were described in negative and restrictive ways. One man explained, "Being driven by voices which are not there and seeing things other people do not see, it is indeed suffering. Only those who have experienced mental illness would understand what I am talking about" (10).

Different expressions were used to describe the suffering such as 'a terrible feeling', and 'a sort of pain'. Suffering could be related to other themes like stigmatisation and discrimination leading to alienation, loss, and fear, while the distress identified by the participants included the devastating effects of mental illness; feelings of chronic tiredness and sorrow; and the debilitating effects of mental illness. One woman said, "It is distressing, to decide whether what you are hearing is real or not" (7). And for many participants suffering was said to be continuous, " it just never ends" (2).

Fear

Several types of fear identified by the participants included; fear of rejection; fear of physical violence against them; fear of being left alone in the world; and fear that normality was irretrievable.

Fear of rejection. One woman, who was fearful of rejection, explained, "The day I got discharged from hospital, I did not know how people were going to receive me back. I was afraid that they would not want to know me any more" (3). Another woman who had experienced rejection said, "I am being rejected by my old friends" (5). The participants seemed to be unwilling to make new friendships because of fear of being rejected. One other woman stated, "It is not easy to make new friends when old ones are rejecting you" (9). Other participants expressed feelings of rejection in relation to social isolation, "Being rejected by friends, I feel totally isolated and I think when my

mother locks me up in the house, I have a lot of time to reflect on my experiences" (6). The feelings of fear of rejection resulted in anger and frustration. One woman with such feelings stated, "forcing them to like me will only frustrate me" (5). And another woman who expressed anger said, "I do not know what to do now, but, anyway, I do not care about friends any more" (1).

Fear of being left alone or feelings of insecurity. All the participants described some fear of being lonely, and this was expressed in terms of feelings of insecurity. "My parents have been there for me, I do not lack in anything, but they are getting old, and I know death is imminent. My worry is who will look after me when they are gone?" (8). This participant had become so dependent on the parents that being alone in the world after the parents were dead was a great threat. Closely related to feelings of being left alone were feelings of insecurity. These included aspects such as lack of confidence, lack of trust, and lack of employment and a resulting lack of money.

The dialogical engagements showed that some of the participants, especially the women, lacked confidence in themselves once they became mentally ill. A statement made by a female participant showed this, "I would not know the reason but since I am a mentally ill, I just do as I am told. I have no control over my life" (2). Another woman who had similar feelings said, "When I am in a group I just keep to myself, I do not say anything" (3). With the men, on the other hand, the major factor contributing to their insecurity and lack of confidence was the lack of money to support their families. One man explained, "There is a lack of resources to assist oneself, no money, no jobs, it means suffering indeed" (10).

Fear of being a bad parent. All but one of the participants who had children, acknowledged a fear of not satisfying their parental role, or of being inadequate parents.

One man sounding very worried said, "I do not know what my children do when I am not here, when I am in hospital," (9). And one woman explained, "When I am in hospital, my parents look after my children, but they are very old now, they cannot control the children. My children lack parental guidance though I try hard to care for them when I am around" (8). Almost all the participants blamed themselves for not being there to support and guide their children, and to teach them socially acceptable behaviours. Related to the fear of being bad parents, feelings of guilt were also evident in other participants' narrations. For example, one woman said, "My son has stopped going to school now. I was not there to encourage him when he needed me" (1). Another woman with a similar conviction stated, "My children have actually been involved in fights with people who laugh at me, in trying to preserve their mentally ill mother's integrity in the community" (3).

Fear of physical abuse. Some of the participants showed fear of physical violence. People in the community associated mental illness with violence. For example one woman said that she had been beaten for no apparent reason, and it was not clear whether or not the people in the community had decided to beat her up because the mentally ill are believed to be aggressive towards them. The woman described, "I have been beaten up without cause, children throwing stones at me, and when I tried to find out what wrong I had done, they started shouting, Mentally ill! Mentally ill! Everybody believed that I had caused the havoc" (7). Similarly, another woman said, "I have been beaten for no apparent reason, gone hungry, begging at times, my personal effects confiscated, all because I am mentally ill" (3). A female participant's description of physical violence included a near rape situation, "I was almost raped at one time, but

had nowhere or no one to report to. You see, people do not believe whatever I say, because I am mentally ill" (2).

Gender Issues

Many of the male participants were still married and depended on their wives to care for them physically and emotionally. The female participants, on the other hand were mostly single. The descriptions of the experiences here were different. The females' descriptions included such terms as 'being alone', not wanted by men', 'divorce'. The females' social isolation was forced on them, whilst men chose to isolate themselves from the society because they did not want to be labelled as failures. One man said, "I have lost credibility in my family because I cannot support them any more, I cannot face them" (7). However, there was one woman whose husband had wanted to maintain the marriage and support her, even though she was mentally ill. She felt it was not right for him to care for her, so she forced him to divorce her. "I think it is a societal expectation, cultural, you know? We believe that a man should be looked after, and not the opposite. That is why I told him to go" (8).

Coping Strategies

From the data, as reported so far, the experience of mental illness was perceived as negative. However, the data also revealed some positive experiences. These positive aspects were categorised by the researcher as coping strategies.

Cultural definition and belief of causation. The first mode of coping was to normalise the experience. This was done by defining their illness as 'kuzungulira mutu', the lesser form of mental illness according to Malawian culture. Another coping strategy included the cultural belief that mental illness is caused by bewitchment. All

the participants believed that their illness was a result of being bewitched. This seemed to lessen anxiety and fostered acceptance of the illness and the hope of a cure.

Networking and Belongingness. 'Belongingness' means personal involvement to the extent that a person feels indispensable and an integral part of the system. In the Malawian context, this was the family system. The participants identified feelings, for example, of belonging to the extended family, of having the support of a spouse (immediate family), and belonging to the church (religious dimension) or being God's own, belonging to God. Such beliefs were expressed in statements such as; "I cannot say that I go hungry because we are all related in the village and my relatives cannot allow me to suffer" (5). Here the participant was showing appreciation of being a part of an extended family system where the belief seemed to be that all the members of the family had an obligation towards the care of their mentally ill relative. Similarly, another woman stated, "My relatives cannot let me suffer with hunger, I cannot be a homeless individual, everybody helps me, especially my relatives" (8). These two statements showed that these mentally ill people gained adequate support from the extended family members. The extended family provided both physical and emotional support to the mentally ill relative.

Apart from the support from extended family members, the immediate family also seemed to play a major role in reinforcing a sense of belonging. One woman revealed, "What I am trying to say is that I depend on my parents and relatives. They support me through my experience, they give me strength to carry on" (2). And another woman contended, "I have been pampered and spoiled by my parents even though I am a mentally ill person (8). Another man asserted, "I depend on my parents for my resources" (7).

Religion. Four out of the eight participants were helped by their religious convictions to accept their conditions. For example, one man said, "With time and prayer we have learnt to live with ourselves. I think prayer is the answer. God gives us strength to go on" (4). A woman explained, "I try to find a reason for my being mentally ill. I pray, I ask God to tell me the reason. I am still waiting for an answer" (1). Another participant stated that he at first thought there was no life after mental illness, and wanted to commit suicide. When his religious convictions awakened in him he decided against it. He said,

> "I at one stage of my illness contemplated suicide. I thought there was no life after mental illness and death was the only answer. After careful thought, I found meaning in my existence. I discovered that God always has a purpose for doing anything, and he had a purpose for letting me become mentally ill. It was up to me to find that purpose. I am glad I did not kill myself at that time because I have noticed that I can reach out to others, help them find meanings in their lives as well" (9).

One woman described the following strategy for handling her condition, "Prayer, I always pray to God to give me strength to carry on, to handle situations in which I land because of my being mentally ill. He gives me courage and strength to take each day as it comes" (3). The sense of belonging, folk conceptualisation of mental illness, and religious convictions fostered acceptance of their conditions.

Self sufficiency. Some of the participants said that mental illness was a disorder just like any other physical disorder, and they felt that people in the community viewed mental illness in that same perspective. Statements like these supported their belief. "People take me as a patient just like any physically ill person. They do not discriminate against my being mentally ill, they understand the suffering I undergo when in the acute phase of the illness" (2). There was indication of acceptance of their predicaments and some of them were enterprising, having their own small businesses, while others

continued to work in paid employment. One woman said, "When I am well, I buy and sell agricultural produce. I make enough money to support myself and my children" (7). A man said, "I am still working. I work in the Ministry of Justice. I get enough money for myself and my family" (4). Another participant said, " I have a lot of thoughts flowing in my head. I repair watches, and I do many more such small businesses. I am self sufficient now, even better than before" (10).

It sounded as if they had accepted that this was the way their lives should be and they were prepared to live them to the full. Even though some of the participants showed a great deal of acceptance of their predicament, some of them nonetheless identified traces of stigmatisation, as discussed earlier.

Not talking about their illness. One other method of coping with their experience was to ignore the topic of mental illness in their discussions. Avoidance of talking about their experiences was identified as a good coping skill by some participants. One participant who used this approach said, "I do not discuss my illness with people, I think it is safer that way" (10). Another participant with similar beliefs indicated, "I do not talk about my condition at all. You are the first person to whom I have opened up" (6).

Living one day at a time. Most of the participants talked of taking each day as it came. Most of them said they were not making plans for the future, their plans only included a few days or weeks ahead. They explained that they never knew when they would have a relapse. Therefore, the way to avoid the frustration of not achieving their plans was to take each day as it came. One participant who employed such a coping strategy said, "I take each day as it comes. This reduces stress" (7). Another participant stated, "I do not know what's in store for me next month, next year, I just live each day

to the fullest, taking my pills to avoid a relapse" (5). Another participant said, "I have experienced lots of surprises in my life, therefore, I do not make many plans any more, I just live each day as it comes" (3).

Summary of Findings

The experience of mental illness according to the participants of this study was similar even though the sample comprised both males and females. The only small difference was identified from their descriptions of coping strategies. Each one of the participants had experienced stigma and discrimination differently and from different sources. Other socially related experiences included social isolation and family disruptions. They had also experienced psychological disturbances in their lives. These were loss, fear, suffering and distress. Some of the participants had experienced near violent physical contacts with other people and expressed fear of being abused physically because of such encounters. All the participants were experiencing a stable mental condition and they attributed this to the prescribed medications that they were taking. However, the participants commented on the side effects of the medications which they were experiencing. These were; tremors, drooling of saliva, and distorted neck muscles (torticollis). Many strategies were used to deal with their changed lives, the most important one being cultural beliefs of causation of mental illness. Other methods of coping were also described. Dealing with stigma, withdrawing from social activities, not talking about their illness to other people, religious involvements and other forms of networking were a source of strength to some participants. Others avoided making long term plans and just took each day as it came. Working and earning money to support their families also served as a means of coping with the experience of mental illness.

CHAPTER SIX

Discussion

This chapter critiques the findings of the study. It is divided into four sections: the discussion of findings and related literature; the theoretical focus of the study, which is based on Parse's theory of human becoming; the implications of this study to practice; and the implications for research.

Findings and Related Literature

View of Their Illness and Cultural Issues

In the traditional Malawian view, mental illness, if defined as 'kuzungulira mutu', the lesser form of mental illness, is received with concern and sympathy. However, the more serious form, 'misala', is usually not talked about. People, both the individual sufferer and the family, suffer in silence. There is a silent stigma attached to 'misala'. This is consistent with the findings of Kuo & Hopkins-Kavanagh (1994) from the Chinese culture, where there is cultural avoidance of talk about mental illness. The only difference between findings from the current Malawian study and Chinese culture is that in Malawi, illness is associated with witchcraft while in Chinese culture, physical illness is always explained as being a result of a dysfunctional organ, but mental illness is seen as a personal weakness (Kleinman, 1988; Kuo & Hopkins-Kavanagh, 1994; Wig, et al. 1980). In the Chinese culture, the individual is blamed for having a mental illness because of personal weakness. Such a belief may reinforce the stigma. On the other hand, the Malawian culture blames witchcraft, which is supernatural, and since nobody can do anything about it, such a belief tries to reduce stigma. In both settings, however, stigma has been identified. As one participant explained, "They avoid you, as if mental illness can be passed" (8).

Nine of the ten participants in the current study described their illness as 'kuzungulira mutu', the lesser form of mental illness according to Malawian culture. This is consistent with other researcher findings such as (Dzurec, 1990; Garrison, 1978; Harwood, 1977; Jenkins, 1988; Swerdlow, 1994). 'Kuzungulira mutu' can be equated with 'nervios' described by the 30 Puerto Rican psychiatric patients studied by Swerdlow (1994), and 'Nerves' which was described by Harwood (1977). Identifying mental illness as the lesser form has been found to be helpful in fostering integration of the mentally ill in a wide range of community networks because it is believed that anyone in the community might suffer from this form of illness. It is said to be a result of stress and everybody experiences some form of stress (Jenkins, 1988). This belief has been shared by several societies of different cultural backgrounds for example Mexican-American, Puerto Rican, and African. However, in all the settings, the stigma still prevailed (Harwood, 1977; Jenkins, 1988; Swerdlow, 1994).

Apart from the cultural-specific definitions of mental illness, there is also a cultural explanatory model of the causes of mental illness which seemed to play a major role in shaping the experiences of mental illness within the sample included in this study. All but one of the participants in the study believed that their illness was caused by bewitchment. Such results confirm the findings of other researchers such as Kuo and Hopkins-Kavanagh (1994) and Shyu (1989) who argued that every society has explanatory models which are sets of ideals about the cause, process, signs and symptoms, meaning, treatment and prognosis of illness. Even though there are many explanatory models in the Malawian culture, for example, spiritual causes, and angry gods (Kleinman, 1980; Mbuluma, 1990; Peltzer, 1987; Wilkinson, 1992), 90% of the participants in this study said that their illness was as a result of being bewitched.

Social Issues

In describing their experiences, the participants talked of stigmatisation and the resultant social isolation. The descriptions were similar to those described by DeNiro (1995) and Vellenga and Christenson (1995), where the participants described experiences of discrimination. One of the participants in the current study said that when his boss discovered that he had been admitted to a mental hospital he wrote him a letter of dismissal which he received on his discharge from hospital. Others have complained that they were unemployed because nobody wanted to employ a mentally ill person.

All the participants in the present study felt that they had suffered some form of discrimination and stigma ranging from being laughed at or being silently rejected, to being unfairly dismissed from work. This concurred with two anonymous authors (1989; 1993), as well as with Hill (1995) and Saris (1995). The descriptions in the literature included people trying to hide the fact that they were mentally ill (Hill, 1995). On the other hand, the participants in this study found it difficult to hide their diagnosis because of the extended family system. Even though most of them did not talk about it, everyone knew what was happening with them. Most of the participants talked of how valuable extended families were and how beneficial they found the support that families rendered, but at the same time, the long string of relatives seemed to reinforce the stigma of mental illness. Furthermore, the families whether they liked it or not, suffered this stigma along with their mentally ill relative (Badger, 1996; Steen, 1996).

Psycho-emotional Issues

All the participants in the current study described changes in their self perceptions, in their attitudes, in their view of life, and the way they related to others.

Their descriptions of the experiences of mental illness were similar to most descriptions found in the literature. The changes described in the literature include perceptions of the self, changes in attention span, change of identity, and change in one's views of life and the level of functioning in life (Freedman & Madison, 1974; Hatfield, 1989; Hill, 1995; Vellenga & Christenson, 1994). Participants in the current study expressed feelings of intense discomfort about their lives ever since they became mentally ill. These feelings were similar to those reported in other studies: "I have suffered enough" (10), "I am frustrated with people's opinions" (7), "frightened, afraid, they beat you for no reason" (8). All the participants in this study expressed fear as one of the experiences in their lives since they became mentally ill. They talked of fear of physical abuse, fear of rejection, of insecurity, or fear of being left alone, and fear of not satisfying their parental role. Experiences of fear were also described by an anonymous author (1989) and Joseph-Kinzelman et al. (1994).

There were descriptions of loss from the participants of this study which were similar to those descriptions made by participants in the study conducted by Vellenga and Christenson (1994). Participants in the current study described loss of job opportunities, loss of relationships, loss of the 'normal self', and loss of independence. On the other hand, Vellenga and Christenson's study found that their participants described two major types of loss only: loss of vocational or job opportunities, and loss of relationships with others.

Loss and stigmatisation led to feelings of distress and suffering. Because of the chronic nature of mental illness, the participants described feelings of anxiety and being 'fed up' with the effects of such a long term illness. This was congruent with findings of Vellenga and Christenson (1994), whose participants described the debilitating and

devastating effects of mental illness, and the feelings of chronically being tired and losing interest in things happening around them. One man in the current study stated, "It has been a very long 10 years. I think I have suffered enough" (9).

Physical and Physiological Issues

Participants perceived use of medication both positively and negatively. All participants described 'long' periods of stability in their conditions and related these periods to their taking of prescribed medication, that is antidepressants or phenothiazines. One participant talked of four years with no hospitalisations. All the other participants had been living in the community with no hospitalisations for periods ranging from 1-3 years. All participants recognised the role of medication in managing the symptoms of their illnesses. On the other hand, they also described their experiences of the side effects of medication. "I experience tremors, saliva drooling and facial muscle distortions" (10). This was expressed as distressing and frustrating because of the need to take the medication to avoid a relapse, and at the same time to live with the side effects which could be severe and embarrassing. The descriptions from participants in the present study are congruent with those of the anonymous author (1989) who lamented, "Initially I had extreme extra-pyramidal symptoms of muscular stiffness and tremors, inner agitation and restless" (p. 33). Usually patients who are taking antipsychotic drugs for a prolonged period of time, or are taking high doses are given other drugs to overcome side effects. This author further stated, "Later, when I started taking procyclidine, which also has side effects, some of the earlier extreme reactions subsided partially" (p. 33). Although participants in the current study did not talk about which drugs they were taking to treat or prevent side effects, their records showed that they were being administered Artane, which is similar to procyclidine.

These are drugs which are prescribed to reduce or prevent side effects of antipsychotic drugs. Despite the use of such drugs, the participants still talked of side effects.

Every participant talked of feelings of loss of control of the self because of the me lication. They described feelings of being happy with their mental state, but at the expense of self control. This description concurred with Hatfield's (1989) study, whose respondents described mixed feelings about medications. They said they were happy with the treatment because the acute phase of schizophrenia tended to abate but the side effects were crippling. Similarly, Joseph-Kinzelman et al. 's (1994) respondents talked of the same experience. One of the respondents in that study stated, "On meds it was too much work trying to be normal" (p. 30). Hill (1995) who was cured of a mental illness, similarly stated, "I continued taking medication though they had side effects, which even now are hard to live with" (p. 55).

Gender Differences

There were four males and six females who participated in this study. The findings showed that women lacked self confidence once they became mentally ill. The men, on the other hand, perceived the failure to support their families as a major worry. Mental illness, whatever the cause, is socially and culturally defined, because it is marked by non-normative behaviour (Crosby, 1987; Kleinman, 1980; Swerdlow, 1994). The critical element in coping with mental illness, according to the male participants and single female parents in the current study, was the degree to which others perceived them to be meeting at least minimal normative expectations, for example, providing for their families. One participant said " now I am seen as a useless being, I cannot provide for my family and relatives. They do not respect me any more" (9). For the female

participants, it was the social recovery, being able to re-establish and maintain relationships (DeNiro, 1995; Frederick & Cotanch, 1995).

Coping with Mental Illness

In an effort to cope with their illness, all the participants in this study described challenging ways of earning money such as continuing work, running a small business, or farming. Financial concerns were mentioned by both male and female participants because most of the female participants were single parents. This was similar to Joseph-Kinzelman et al.'s (1994) findings where 73% of the respondents described financial concerns and the way they tried to cope by looking for work.

Participants also described other forms of coping with their illness. These were consistent with findings from other studies. The coping strategies included active participation in treatment plans (Saris, 1995), accepting their condition and looking for alternative health ways of living (Vellenga & Christenson, 1994), and religious and spiritual involvement (Anonymous, 1989). The most frequently mentioned coping strategy was the belief that everybody's destiny was calculated by God and that there is a reason for all experiences. All the participants said they always prayed and were waiting for God's answer. Church attendance and prayer meetings gave them hope and a means for networking with other believers. Networking has been described by many researchers as a means of coping with mental illness (Laing, 1994; Solokovsky, 1978; Trimble, 1981). Networking results in a sense of belonging which is a human need (Reinhard, 1994; Solokove & Trimble, 1986; Wilkinson, 1991).

Most of the participants in this study also described not talking about their illness and living each day as it came, as a means of coping with their illness. Such methods of coping were also found in the descriptions of an anonymous author (1989)

and Joseph-Kinzleman et al. (1994). Participants explained that they thought keeping silent about their illness was one of the best ways of coping because other people would not know that they were mentally ill. This would, therefore, prevent them from experiencing the stigma of mental illness. Similarly, the participants in Joseph-Kinzelman et al.'s (1994) study, said that by admitting their problems with hallucinations, other people would avoid them forever.

Findings and Theoretical Focus

Being diagnosed mentally ill is completely devastating to the individual, as one man indicated, "There is nothing I can do, I am a mentally ill individual, and that's it" (10). Through the expression of their different experiences, the participants in this study conveyed the life changes and coping strategies they had to use in order to continue living a meaningful existence. Their experience was that of being thrust suddenly into self-conscious living which is surrounded by chronic sorrow. This in turn prompted them to re-examine their lives to find out who they were and what they were doing with their lives. This re-evaluation of the present can be equated with valuing in the first principle of Parse's (1981) theory .

Valuing

Despite the participants' descriptions of suffering, stigma, alienation, and feelings of being fearful of the future, they had, however, devised mechanisms to cope with their experiences. All the participants described the importance of the lost normal self, the shattered dreams, and the future which was blurred. Despite such feelings, they were still trying to uncover ways of going on living amidst such intense suffering and loss. A sense of intense suffering and loss with yearning for cherished dreams and hopes relates to the theoretical concept of valuing. Parse's (1981) first principle states,

"Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging" (p. 42). Valuing relates to choosing meaning in a situation. Parse believed that human beings in interrelationships with the universe cocreate meanings at many different levels and that they make lived choices as they move towards cherished dreams and hopes. This is the process of becoming. Frankl (1992) and Parse (1992) asserted that human beings will always find meaning in any situation regardless of how hopeless it may seem. Mental illness might be seen as the end of normal living to other people, but to the persons suffering the illness, cocreating with the universe and others reveals value priorities in the meaning they assign to their experience. This meaning is reflected in the individual's pattern of living. This is defined as human becoming, or as 'health' (Parse, 1981).

One of the participants in the present study said, " I wanted to kill myself at one stage during my illness. But I gave it a lot of thought, and told myself that God has a purpose in everything He does. He had a reason for allowing me to be mentally ill" (10). This was an example of valuing and finding a purpose for moving on with life and accepting the situation. This particular participant did not live for only the now moment, but valued his situation and decided to move beyond the now moment towards human becoming, thereby exemplifying Parse's first principle.

Revealing-Concealing, Connecting-Separating

The second principle of Parse's theory is "Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing, enabling-limiting, and connecting-separating" (Parse, 1981, p. 50). This principle describes the unity of the human being's rhythmical patterns of interrelating with the world which is revealed in the human being's living both sides of a rhythm, even though one side may be

predominant over the other at any given moment (Parse, 1981, 1987). With the participants in this study, the theme of rhythmicity is reflected in their individual ways of revealing and concealing the experience, while connecting and separating the opportunities and limitations of schizophrenia and bipolar affective disorders. The participants were able to talk about their experiences but at the same time conceal some stories about the experiences. This might be culturally related, but according to Parse, this is the process of becoming, where individuals wish to reveal, but at the same time conceal part of the experiences. One participant revealingly explained, "Being mentally ill is a painful experience" (8). When asked to describe the 'painful experience', she just said, "uhf! they laugh at us", and kept silent. She did not describe much about the experience, and so it may be concluded that she was concealing the rest of the experience.

The participants in this study spoke of either being supported or wanting to be supported by a loving family and friends. In speaking about relationships, participants were anguished by rejection from family and friends. Participants described periods of solitude which mingled with times of communication as they talked of being with and distancing themselves from those who did not want to associate themselves with them. The following example illustrates this: "I talk to those who talk to me , and I do not talk to those who do not want to associate themselves with me" (5). This statement is related to connecting-separating in Parse's second principle. Participants in this study were, therefore, living the paradoxical unity of revealing-concealing and connecting-separating as a pattern of health.

Transforming

The participants in this study showed that despite being affected by schizophrenia or having a bipolar affective disorder, they had to continue living. This is consistent with Parse's (1981) third principle of contranscendence, "Contranscending with the possibles is powering unique ways of originating in the process of transforming"
(p. 50). This principle describes the process of mobilising creative ways of moving beyond the now moment towards the unfolding of possible ways of living. In speaking about the future, each participant described struggling to go on living with either schizophrenia or bipolar affective disorder. Most of the participants questioned themselves and their beliefs in God, and made decisions to go on moving beyond the now moment, believing God would answer their prayers. Most of the participants made decisions to do something for themselves to earn a better living, for example, starting a small business or continuing with work. The participants decided to move beyond the now moment by drawing on their personal strength and faith which suggests powering, according to Parse's theory. Each of the participants described unique and creative ways of living in the process of becoming. Parse described health as an open process of becoming. Thus, in suffering the stigma of mental illness and all the related effects of mental illness, the participants were living health as a process of becoming. They were able to make their own creative ways of living with the disabling conditions of schizophrenia and bipolar affective disorders.

Implications for Practice

The participants in the current study were able to provide a source of information, describing their experiences, though at a relatively superficial level. They

were not able to give an in-depth narration of their experiences probably because of the culture of non-disclosure and also because mental illness is a highly stigmatised illness according to the findings of this study. The fact that they were able to describe their experiences at all is congruent with Hatfield (1989), Steeves and Kahn (1986) and McGrath (1984). The participants were able to describe their self perception, how other people viewed them, and what mental illness meant to them. Most of the participants also described coping strategies they adopted to cope with their illness.

The goal in psychiatric nursing is to provide high quality care to the patients, assisting them to develop healthy coping skills to cope with everyday life. It would be difficult to assist them to cope with everyday life if the meaning they attribute to their experience is not known. In psychiatric nursing, psychotherapeutic management is adopted as the prescribed model of care. Psychotherapeutic management is a therapy encompassing nurse-patient relationship, psychopharmacology , and milieu management (Keltner, Schwecke & Boston, 1991). In order for the psychiatric nurse to provide this psychotherapeutic management, she/he must understand what the person living the experience thinks is the meaning of the experience. This is the essence of psychiatric nursing. McFarland and Thomas (1991) explain that for the nurse to provide effective and efficient care, she/he must develop an understanding of the patients' perceptions of their experiences and situations confronting them must be developed.

Kleinman (1980, 1988) pointed out that the meaning of illness is culture-specific and that each culture must be studied to identify the meaning of lived experiences of illness in that particular context. This would result in the provision of effective nursing care which is culturally appropriate. The findings of the current study are congruent with Kleinman's because the participants defined their illness as

'Kuzungulira mutu', a lesser form of mental ill , even though they had suffered a major form of mental illness, 'Misala'. A person who does not understand the cultural definitions and the attempts of the Malawian people to reduce the stigma of mental illness by describing their illness as a lesser form, might misdiagnose and thereby mismanage a patient. Similarly, Jenkins (1988) asserted that culturally appropriate nursing care could only be rendered if each culture is studied and the meanings of the experiences are understood by the health personnel.

Qualitative studies can generate a direction for nursing knowledge and practice. It has been psychiatric-mental health nursing's struggle to reduce the stigma of mental illness, but it seems the current strategies are not working. Cognitively based knowledge alone of how to care for the me..tally ill might not be sufficient to prepare a psychiatric-mental health nurse to be able to provide high quality care to patients, as well as assume positive attitudes, and assist in reducing stigma of mental illness and its related suffering. Holistic and humanistic perspectives including counselling and interviewing skills need to be reinforced and addressed in the nursing curriculum in this setting so that the nurse is well equipped to assist patients to live comfortably as they cocreate with others in the community in their process of becoming.

This study has implications for other health care workers as well as members of the public. Many participants in this study experienced loss of jobs, unemployment, rejection by friends, physical violence and social isolation. Public education may help in changing people's attitudes towards mental illness, thereby reducing stigma. If the public is educated about mental illness, the mentally ill may be encouraged to form networks for those with schizophrenia, or groups for those suffering bipolar affective disorder.

Implications for Research

The participants in this study may not represent the larger group of people living with schizophrenia and bipolar affective disorders in Malawi. Therefore, it is necessary that further research be conducted to validate the findings of this descriptive study. Research in mental health in Malawi is in its infancy. More must be known about the lived experiences of the mentally ill so that more informed culturally acceptable nursing care, can be provided for the mentally ill.

The aim of this study was to investigate individual experiences of adults living with mental illness. The analysis of this study, however, does not permit the researcher to conclude that all mentally ill persons diagnosed with schizophrenia and bipolar affective disorders will give similar descriptions of their experiences. This limitation arises owing to the small sample size and purposive sampling method employed. The sample consisted of 10 participants, including males and females of different age groups, and those who were diagnosed with schizophrenia and bipolar affective disorders. It is therefore, recommended that studies of homogeneous groups be carried out to enable researchers to unfold the reality of living with mental illness and uncover the limitations of this study.

This study of four men and six women, found that experiences regarding social support and coping strategies were slightly different. The females depended more on others whilst the male participants chose the more isolative methods of coping. Research in relation to gender issues and coping skills in the mentally ill persons need to be conducted to validate the findings of the current study.

Suffering, stigma and loss were concepts described by many participants in this study. It is necessary, therefore to explore more about these aspects. Available

literature says in African culture, because of close family ties, family members assist each other to cope with crisis. At least to some extent, this was not found to be happening with participants in the current study. It would also be necessary to study all tribes in Malawi to explore their experiences of mental illness. Different age groups also need to be studied to find out if experiences vary with age.

The theoretical framework in this study was guided by Parse's (1981) theory of Human Becoming. The findings of this study may encourage the use of this model in all areas of nursing, including nursing research, practice, education and administration.

Conclusion for the Study

The purpose of this study was to describe the experience of being mentally ill. The findings of this study indicated that mentally ill persons experience many changes in their lives but manage to develop coping skills. The descriptions of their experiences were analysed by the researcher and eight major categories emerged; view of their illness, view of self, other people's views, stigma and discrimination, loss, fear, gender differences, and coping strategies.

The participants' views of their illness was shaped by cultural orientation. This included the definition of their illness and their description of causation of mental illness. The participants described their illness as 'kuzungulira mutu' and the cause as witchcraft. In the Malawian culture, kuzungulira mutu being a lesser form of mental illness is received with concern and sympathy. Mental illness caused by witchcraft is also received with same feelings of concern and sympathy. Such outlook of mental illness reduces the stigma of the illness.

However, stigma was still described by all the participants as an everyday experience of their lives. They were being discriminated against in the work place and

in the community. The study participants experienced changes in their personalities, changes in the ways they related with others, and in their attitudes to life. Most of the participants thought their existence was blurred with no or little hope of being normal again. They experienced loss of relationships, loss of personal effects and loss of job opportunities. The experience of suffering and the pervasive feelings of distress were also related to their illness.

All had developed strategies to deal with their experiences. Avoiding social contact, not talking about their illness to other people, living each day as it came, religious involvements, and maintain a job and/ or having a small business to earn money to support themselves and their families, were the coping strategies described by the participants of the study. Being able to provide for their families, and the degree to which other people perceived them to be meeting the normative expectations of assuming the breadwinners' role, was the most critical element in coping with their experience.

The experience of living with mental illness in this study lead to the conclusion that such an experience had a major impact on the day to day living. The experience of stigma and discrimination, the chronic nature of the illness, dependence on prescribed medication and its related side effects, loss, and fear, all made living with the illness a blurred existence. The participants were able to evaluate their experiences and developed coping strategies.

Parse's theory of human becoming enabled the researcher to explain human response to living with mental illness. The findings indicated that the participants were able to value their present mental state and their lives in general and uncovered ways of going on living amidst the intense suffering and loss. The participants revealed their

experiences and at the same time concealed other experiences. All in all, they were able to make their own creative ways of living with the disabling conditions of schizophrenia and bipolar affective disorder.

References

Achiterberg, J. (1990). Woman as healer. Boston: Shambhala.

Anonymous. (1989). First person account: How I've managed chronic mental illness. Schizophrenia Bulletin, 15 (4), 17-20.

Anonymous. (1993). Coming out: My experience as a mental patient. Journal of Psychosocial Nursing, 31 (5), 17-20.

Anscombe, R. (1987). The disorder of consciousness in schizophrenia. Schizophrenia Bulletin, 13 (2), 241-260.

Ayodele Tella, W. (1987, January). Modalities of traditional medical practices and the Malawian scene. Paper presented at the First National Seminar on Traditional Medicine, Mangochi, Malawi.

Baier, M. S. (1995). Uncertainty of illness for persons with schizophrenia. Issues in Mental Health Nursing, 16 (3), 201-212.

Badger, T. A. (1996). Living with depression: Family members' experiences and treatment needs. Journal of Psychosocial Nursing, 34 (1), 21-29.

Banes, J. S. (1983). An ex-patient's perspective of psychiatric treatment. Journal of Psychiatric Nursing and Mental Health, 21 (3), 11-19.

Barnard, K. (1981). Research designs: Descriptive methods. Maternal and Child Nursing, 6, 243.

Beck, C, T. (1993). Teetering on the edge: A substantive theory of postpartum depression. Nursing Research, 42 (1), 42-48.

Ben-Tovim, D. T. (1987). Development of psychiatric mental health in Botswana. New York: Tavistock.

Beverley, J., Douglas, S., & Hughes, L. (1990). Staying well: Factors contributing to successful community adaptation. Journal of Psychosocial Nursing, 28 (6), 19-24.

Breitmayer, B.J., Ayres, L., & Knafl, K. (1993). Triangulation in qualitative research: Evaluation of completeness and confirmation purposes. Journal of Nursing Scholarship, 25 (3), 237-243.

Brooker, C., & White, E. (1993). Community psychiatric nursing. London: Chapman and Hall.

Brydolf, M., & Segesten, K. (1995). Living with ulcerative colitis: Experiences of adolescents and young adults. Journal of Advanced Nursing, 23 (1), 39-47.

Burdekin, B., Guilfoyle, D. M., Hall, D. (1993). Human rights and mental illness. Report of the national inquiry into the human rights of people with mental illness. (Vol.1). Canberra, Australia.

Burns, N., & Grove, S. K. (1987). The practice of nursing research. Conduct, critique and utilise. Philadelphia: Saunders.

Cheng-Louie, T. (1981). Nursing care of Chinese in American patients. In M. S. Orque, B. Bloch, & L.S.A. Monroy. (Eds.), Ethnic nursing care: a multicultural approach. pp. 183-218. St. Louse: C. V. Mosby.

Chinn, L.P. (1994). Advances in methods of inquiry for nursing. Maryland: Aspen.

Chrisler, J., & Howard, D. (1992). New directions in feminist psychology. Practices, theory and research. New York: Springer.

Cody, K. W. (1994). Meaning and mystery in nursing science and art. Nursing Science Quarterly, 7 (2), 48-51.

Community Health Science Unit. (1994). Basic health statistics. Report no. 17, Lilongwe: Malawi.

Coward, D. (1987). The lived experience of self-transcendence in women with advanced breast cancer. Nursing Science Quarterly, 3,162-169.

Crawford, T. (1995). Traditional healers and psychiatric health care. South African Medical Journal, 85 (4), 291-292.

Crosby, R.L. (1987). Community care of the chronically mentally ill. Journal of Psychosocial Nursing, 25 (1), 33-37.

Davis, A. J. (1981). Compassion, suffering, morality: Ethical dilemmas in caring . Nursing Law and Ethics, 2 (1), 2-6.

Davis, D. K., & Cannava, E. (1995). The meaning of retirement for communally living retired performing artists. Nursing Science Quarterly, 8 (1), 8-16.

Davitz P., & Davitz, D. K. (1981). Nurses' inference of suffering and illness. Journal of Advanced Nursing, 11 (3), 623-631.

DeNiro, A. D. (1995). Perceived alienation in individuals with residual schizophrenia. Issues in Mental Health Nursing, 16 (3), 185-200.

Dossey, L. (1991). Space, time and medicine. Boulder, Co: Shambhala.

Downe-Wamboldt, B. (1992). Content analysis, methods, applications and issues. Health Care for Women International, 13, 313-321.

Dzurec, L.C (1990). How do they see themselves? Self-Perception and functioning for people with chronic schizophrenia. Journal of Psychosocial Nursing, 28 (8), 10-14.

Edgerton, R. (1965). Conceptions of psychosis in four African societies. American Anthropologist, 2, 408-425.

Elwell, P., & Gillespie, F. (1995, December, 5). TV report from Hobart Hospital in Tasmania on mental heath. Perth: Channel 7, WA Public Broadcasting Service.

Fadden, G., Bebbington, P., & Kuipers, L. (1987). Caring and its burdens: A study of spouses of depressed patients. British Journal of Psychiatry, 151, 660-667.

Field, A. P., & Morse, J.M. (1990). Nursing research: The application of qualitative approaches. London: Groom Helm.

Flaskerud, J. H. (1986). Profile of chronically mentally ill psychotic patients in four community mental health centers. Issues in Mental Health Nursing, 8 (2), 155-167.

Frankl, V. E. (1992). Man's search for meaning : An introduction to logotherapy. New York: Pocket Books.

Frankl, V. E. (1962). The will to meaning. New York: New American Library.

Frederick, J., & Cotanch, P. (1995). Self-help techniques for auditory hallucinations in schizophrenia. Issues in Mental Health Nursing, 16, 213-224.

Freedman, B. J., & Madison, M. A. (1974). The subjective experience of perceptual and cognitive disturbances in schizophrenia. Archives of General Psychiatry, 30, 333-340.

Garrison, V. (1978). Social support of schizophrenic and non schizophrenic Puerto Rican women in New York City. Schizophrenia Bulletin, 4, 561-596.

Glaser, B.G., & Straus, A. L. (1967). The discovery of grounded theory. New York: Aldine.

Guba, E.G., & Lincoln, Y. S. (1981). Effective evaluation. San Francisco: Jossey-Bass.

Hartigan del Campo, E.,J., Carr, C. F., & Correa, E. (1983). Rehospitalised schizophrenics: What they report about illness, treatment, and compliance. Journal of Psychiatric-Mental Health Nursing, 21 (6), 29-33.

Harwood, A. (1977). Spirits as needed: A study of Puerto Rican community mental health resource. New York: Wiley.

Hatfield, A.B. (1989). Patients' account of stress and coping in schizophrenia. Hospital and Community Psychiatry, 40 (11), 1141-1145.

Hazelton, M. (1993). The discourse of mental health reform: A critical analysis. Australian Journal of Mental Health Nursing, 2 (4), 144-154.

Hicks, M. B. (1989). Analysis of circumstances which precede the rehospitalisation of individuals with chronic schizophrenia. Issues in Mental Health Nursing, 10 (3), 137-147.

Hill, P. (1995). The aftermath of diagnosis. Nursing Times, 99 (144), 55-56.

Hitchens, E. A. (1977). Helping psychiatric outpatients accept drug therapy. American Journal of Nursing, 77 (3), 464-466.

Holsti, O. R. (1969). Content analysis for social sciences and humanities. Ontario: Addision-Wesley.

Horace, M. S. (1936). An investigation concerning mental disorder in the Nyasaland (now Malawi) natives. The Journal of Mental Science 341, 702-730.

Hsu, J. (1974). Mental health in Chinese culture. In W. Lebra. (Ed.), Culture and mental health research in Asia and the Pacific (pp.97-108). Honolulu: University of Hawaii Press.

Iwasiw, C. L., & Olson E. (1995). Content analysis of nonprofessional caregiver-patient interaction in long-term care facilities. Clinical Nursing Research, 4 (4), 411-424.

Jack, D. (1991). Silencing the self: Women and depression. Massachusetts: Harvard University.

Jenkins, J. (1988). Ethnopsychiatric interpretations of schizophrenic illness: The pattern of Nervios with Mexican-American families. Culture, Medicine and Psychiatry, 12 (3), 301-329.

Joseph-Kinzelman, A., Taylor, J., Rubin, W., Ossa, J., & Risner, P.B. (1994). Clients' perceptions of involuntary hospitalisation. Journal of Psychosocial Nursing, 32 (6), 28-32.

Kahn, D. (1992). Ways of discussing validity in qualitative nursing research. Western Journal of Nursing Research, 15 (1), 122-126.

Kahn, L. D., & Steeves, R. H. (1986). The experience of suffering: Conceptual clarification and theoretical definition. Journal of Advanced Nursing, 11 (6), 623-631.

Kapapa, P. (1980). Witchcraft and bewitchment as a social contract. Malawi Medical Journal, 3 (2),11-12.

Katz, M., Marsella, A., Dube, K. C., Olatawura, M., Takahashi, R., Nakane, Y., Wynni, L., Gift, T., Brinnan, J., Sartorius, N., Jablensky, A. (1988). On the expression of psychosis in different cultures: Schizophrenia in Indian and Nigerian communities. Culture, Medicine, and Psychiatry, 12 (3), 331-355.

Keen, E. (1975). A primer in phenomenological psychology. New York: Holt, Rinehart and Winston.

Keltner, N.L., Schwecke, L.H., & Boston, C.F. (1991). Psychiatric nursing: A psychotherapeutic management approach. St Louis: Mosby.

Kleinman, A. (1973). Medicine in Chinese cultures. Forgety International Centre: Bethesda.

Kleinman, A. (1980). Patients and healers in the context of culture. Berkeley: University of California Press.

Kleinman, A. (1988). Rethinking psychiatry: From cultural categories to personal experience. New York: Free Press.

Knafl, K. A., & Howard, J. M. (1984). Interpreting and reporting qualitative research. Research in Nursing and Health, 7 (7), 17-24.

Krippendorff, K. (1980). Content analysis: An introduction to its methodology. Beverley Hills, California: Sage.

Kuo, C. L., & Hopkins-Kavanagh, K.H. (1994). Chinese perspectives on culture and mental health. Issues in Mental Health Nursing, 15 (6), 551-567.

Laing, R. D. (1994). Transcendental experience in relation to religion and psychosis. Spiritual emergency. Kundalini: Krishna Publications.

Laws of Malawi. (1968). The Mental Treatment Act. Lilongwe: Malawi Government Print.

LeCompte, N., & Goetz, B. (1982). Problems of reliability and validity in ethnographic research. Review of Educational Research, 52 (1), 31-60.

Lin, K. M. (1981). Traditional Chinese medical beliefs and their relevance for mental illness and Psychiatry. In A. Kleinman and Y. Lin (Eds.). Normal and abnormal behaviour in Chinese cultures (pp. 357-369). The Netherlands: Dordrecht.

Lin, T. (1983). Psychiatry and Chinese culture. The Western Journal of Medicine, 139, 862-867.

Lomas, (1967). The psychiatric patient's' perspective. In Frankl, V. E. (1992). Man's search for meaning: An introduction to logotherapy. New York: Pocket Books.

Mason, D. J. (1981). An investigation of the influences of selected factors on nurses' inferences of patients suffering. Journal of Nursing Studies, 18, 251-259.

Mbuluma, E. L. (1990). The mental health state in Malawi. Limbe: Assemblies of God Literature Centre Press.

McFarland, G. K., & Thomas, M. D. (1991). Psychiatric mental health nursing. Philadelphia: J. B. Lippincott.

McGrath, M. E. (1984). First person account: Where did I go? Schizophrenia Bulletin, 10, 635-640.

Miles, M. B., & Huberman, A. M. (1984). Qualitative data analysis: A source book of new methods. Beverley Hills, California: Sage.

Ministry of Health. (1976). Health for all by the year 2000. Malawi, Lilongwe.

Mitchell, G.J. (1990). The lived experience of taking life day-by-day in later life: Research guided by Parse's emergent method. Nursing Science Quarterly 3 (1), 29-36.

Montbriand, M. J., & Laing, G. P. (1991). Alternative health care as control strategy. Journal of Advanced Nursing 16 (3), 325-332.

Morse, J. M. (1991). Qualitative nursing research: A contemporary dialogue. London: Sage.

Msukwa, L. A. H. (1981). Meeting the health care needs of rural Malawi: An alternative strategy. University of Norwich, Norwich: University of Alia Press.

Munhall, P.L. (1994). Revisioning phenomenology. Nursing and health science research. New York: National League for Nursing Press.

Munhall, P., Oiler, C. (1986). Nursing research: A qualitative perspective. Norwalk: Appleton-Century-Crofts.

National Mental Health Strategy. (1996). What is stigma?. Commonwealth\State Initiate. Australia.

Oberst, M. T. (1978). Nurses' inference of suffering: The effects of nurse patient similarities and verbalisation of distress. Clinical Perspectives in Nursing Research, 38-60.

Omery, A. (1983). Phenomenology : A method for nursing research. A qualitative perspective. Advances in Nursing Science. 5 (2), 49-63.

Parse, R., Coyne, A. B., Smith, M. J. (1985). Nursing research. Qualitative methods. Bowie: Brady Communication Company.

Parse, R.R. (1981). Man-Living-Health: A theory of nursing. New York: Wiley.

Parse, R.R. (1987). Man-living health theory of nursing. In R. R. Parse, Nursing Science: Major paradigms, theories and critique. (pp.159-180). Philadelphia: Saunders.

Parse, R.R. (1992). Human becoming, Parse's theory of nursing. Nursing Science. Quarterly, 5 (1), 35-42.

Patton, M. Q. (1990). Qualitative methods (2nd ed.). Newbury Park, California: Sage.

Peltzer, K. (1987). Some contributions of traditional healing practices towards psychosocial health care in Malawi. Unpublished doctoral dissertation, University of Malawi, Lilongwe.

Perese, E. F. (1997). Unmet needs of persons with chronic mental illness: Relationships to their adaptation to community living. Issues in Mental Health Nursing, 18 (1), 19-34.

Phillips, J. R. (1993). Researching the lived experience: Visions of the whole. Nursing Science Quarterly, 6 (4), 166-167.

Porter, E. J. (1994). Reducing my risks: A phenomenon of older widows' lived experience. Advanced Nursing Science, 17 (2), 54-65.

Quupe, L. (1990). Factors contributing to the cause of mental illness in South Africa. Unpublished doctoral dissertation. Sterkfontein College of Psychiatric Nursing, Johannasberg.

Reed, M. (1989). Mental health of older adults. Western Journal of Nursing Research, 11, 143-162.

Reinhard, S. C. (1994). Living with mental illness: Effects of professional support and personal control on caregiver burden. Research in Nursing and Health, 17, 79-88.

Robertson, J. (1994). Handbook of clinical nursing research. Melbourne: Churchill Livingstone.

Roper, J. M., & Anderson, N. L. R. (1994). Qualitative perspectives: Clinical Nursing Research, 3 (4), 294-296.

Russo, N. (1990). Overview. Forging research priorities for women's mental health. American Psychologist, 45 (3), 368-373.

Salima, M. (1987, January). Traditional and modern medical practices in Malawi. A paper presented at the First National Seminar on Traditional Medicine, Mangochi, Malawi.

Sandelowski, M. (1986). The problem of rigour in qualitative research. Advances in Nursing Science, 8 (3), 27-33.

Sandelowski, M. (1995). Focus on qualitative methods: Sample size in qualitative research. Research in Nursing and Health,18 (1), 179-183.

Saris, J.A. (1995). Telling stories: Life histories, illness narratives, and institutional landscapes. Culture, Medicine and Psychiatry, 19 (1), 39-72.

Siegel, B. S. (1989). Peace, love, and healing body mind communication and the path to self-healing: An exploration. New York: Harper & Row.

Seidman, I. E. (1991). Interviewing as qualitative research. New York: Teachers College Press.

Shyu, Y. I. (1989). Intervening with families of demented elderly. Journal of Nursing (Taiwan), 36 (2), 25-34.

Smolan, R., Moffart, P., & Naythons, M. (1990). The power to heal: Ancient arts and modern medicine. New York: Prentice Hall.

Sokolovsky, J. (1978). Schizophrenia and social networks: Ex-patients in the inner city. Schizophrenia Bulletin, 4 (4), 546-560.

Solokove, R.L., Trimble, D. (1986). Assessing support and stress in the social networks of chronic patients. Hospital and Community Psychiatry, 37 (4), 370-372.

Speedy, S. (1993). The search for meaning in caring for the mentally ill people. The Australian Journal of Mental Health Nursing, 2 (4), 170-182.

Steen, M. (1996). Meaning of recovery from clinical depression for middle-adult women: A phenomenological study. Issues in Mental Health Nursing, 17 (2), 73-92.

Steeves, R., & Kahn, D.L (1986). Experience of meaning in suffering. Journal of Nursing Scholarship, 19 (3), 114-116.

Streubert, H.J. & Carpenter, D. R. (1995). Qualitative research in nursing: Advancing the humanistic imperative. Philadelphia: J.B Lippincott.

Stuart, G., & Sundeen, S. (1995). Principles and practice of nursing (5th Ed.). St Louis: Mosby.

Swerdlow, M. (1994). "Chronicity", "Nervios", and community care: A case study of Puerto Rican psychiatric patients in New York City. Culture, Medicine and Psychiatry, 16 (2), 217-235.

Talley, B., & Coleman, M. A. (1992). The chronically mentally ill: Issues of individual freedom versus societal neglect. Journal of Community Health Nursing, 9 (1), 33-41.

Taylor, B. (1993). Phenomenology: One way to understanding nursing practice. International Journal of Nursing Studies, 30 (2) ,171-178.

Thorne, S. (1991). Methodological orthodox in qualitative nursing research.: Analysis of the issue. Qualitative Health Research, 1 (12), 178-199.

Trimble, D. (1981). Community network therapy: Strengthening the net works of chronic patients. International Journal of Family Psychiatry, 2, 116-118.

Tseng, W.S., & Wu, D.Y.H. (1985). Chinese culture and mental health. Miami: Academic Press.

Turale (1994). Ballarat Koorie life experiences: Learning about Koorie perceptions of mental illness. Australian Journal of Mental Health Nursing, 3 (1), 16-28.

Upvall, M.J. (1992). Nursing perceptions of collaboration with indigenous healers in Swaziland. International Journal of Nursing Studies, 29 (1), 22-36.

Van Putten, T. (1974). Why do schizophrenic patients refuse to take their drugs? Archives of General Psychiatry, 31, 67-72.

Vellenga, B. A., & Christenson, J. (1994). Persistent and severely mentally ill clients' perceptions of their mental illness. Issues in Mental Health Nursing, 15 (4),359-371.

Walshe, C. (1995). Living with a venous leg ulcer: A descriptive study of patients' experience. Journal of Advanced Nursing, 22 (6), 1092-1100.

Warner, C. (1983). Recovering from schizophrenia in the Third World. Psychiatry, 3, 197-212.

Wig, N., Suleiman, M. A., Routledge, R., Murphy, R., Ladrido-Ignacio, L., Ibrahim, H. H. A., & Harding, T. W. (1980). Community reactions to mental disorders: A key informant study in three developing countries. Acta Psychiatrica Scandinavia, 61, 111-126.

White, G. M. (1982). The role of cultural explanation in somatization and psychologization. Social Science and Medicine, 16, 1519-30.

Wilkinson, M. (1991). A mental health handbook for Malawi. Limbe: Assembles of God Literature Centre Press.

Wilkinson, M. (1992). Malawi's mental health service. Malawi Medical Journal, 8 (1), 10-14.

Williamson, J.C. (1975). Useful plants of Malawi. Zomba: University of Malawi.

World Health Organisation Report. (1976a & b).Traditional medicine and health services development in Africa. WHO Chronicle 30, 511-512.

World Health Organisation Report. (1991). Organisation of mental health services in developing countries: Sixteenth Report of Expert Committee on mental health. (World Health Organisation Tech. Rep. Ser. No. 564). Geneva: WHO

Wittkower, E. D., Dubreuil, G. (1973). Psychocultural stress in relation to mental illness. Social Science & Medicine, 7, 691-704.

Yalom, D. I. (1982). The 'Terrestrial' meanings of life. International Forum for Logotherapy,5 (2) ,92-102.

Appendix A

Consent form and letter to the participants.

My name is Ivy Lekera, I am presently a student at Edith Cowan University in Australia, doing a Master of Nursing degree. But I am a nurse who has been working as a psychiatric- mental health nurse for four years now , and I have always wondered what it means to be mentally ill. I have always thought I am missing out something in caring for people who are mentally ill, because I have used my frame of reference in assisting those who seem to have lost the will to live. This is the opportune time for me to find out the meaning of the experience of mental ill as lived by the individual sufferers.

As a fulfilment of the Master of Nursing degree, I am required to carry out research. Since my interest has always been offering high quality mental health service to the people, I would like to find out the meaning of the experience of mental illness as lived by the clients. I will be interviewing those patients clients living in the community in Zomba.

The results will be used to add on to the body of knowledge of the psychiatric-mental health nurses, to be used to improve care and interventions.

Participation is voluntary. You can withdraw from the study at any time. Your health will not be affected in any way. Confidentiality will be maintained, nobody apart from me will read the fieldnotes or listen to the tape . No names will be used, just a code which will be known to me alone will be used.

If you are willing to participate in the study please sign the consent form

I ---------- have read the above and willing to participate in the study. I understand that participation is voluntary.

Signed ----------.

Witness ----------.

Date ----------.

EDITH COWAN UNIVERSITY
PERTH WESTERN AUSTRALIA
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OFFICE OF RESEARCH AND DEVELOPMENT

Pearson Street, Churchlands
Western Australia 6018
Telephone (09) 273 8170
Facsimile (09) 273 8046

Committee for the Conduct of Ethical Research

Ms Ivy Lekera
[redacted]

Dear Ms Lekera

Re: **Ethics Approval**

Code: 95-164

Project Title: *The meaning of the experiences of mental illness in an adult population in Zomba, Malawi: A phenomenological study.*

This project was reviewed by the Committee for the Conduct of Ethical Research at its meeting on 24 November 1995.

I am pleased to advise that the project complies with the provisions contained in the University's policy for the conduct of ethical research, and has been cleared for implementation.

Period of approval is from 1 January 1996 to 31 January 1997.

Yours sincerely

[redacted]

ROD CROTHERS
Executive Officer

28 November 1995

Please note: Students conducting approved research are required to submit an ethics report as an addendum to that which they submit to their Faculty's Higher Degrees Committee.

cc: Ms Heather McAlpine, Supervisor
Mrs Gerrie Sherratt, Secretary H.D.C.

[redacted]

CAPITAL CITY
LILONGWE 3
MALAWI

15/04/96

[redacted]
AUSTRALIA.

Dear Ms Lekera,

RE: THE MEANING OF EXPERIENCES OF MENTAL ILLNESS IN AN ADULT POPULATION IN ZOMBA MALAWI: A PHENOMENOLOGICAL STUDY

I would like to inform you that the Health Sciences Research Committee approved the study and advised that you should collaborate with the just formed Mental Health Research Committee. The need to disseminate the results was also emphasized.

I wish you all the best in your studies.

Yours sincerely,

[redacted]

B.P.L.MATYATIYO
RESEARCH OFFICER
for: Secretary for Health and Population

Appendix B

Demographic Information

Age.....Gender.....

Diagnosis.....

When first diagnosed.....

Medications.....

Other health problems.....

Level of

Education.....

Family History in relation to mental illness

.....

.....

.....

Living arrangements

Marital status.....

Children.....

Who else in the house.....

Interview Question Prompts Guide.

Participants will be asked to share their thoughts, feelings, perceptions and circumstances that they associate with mental illness. Participants will also be asked to describe the meanings that they associate with being mentally ill, and a description of the strategies they have used to help resolve the issues involved.

Sample of prompts may include the following:

What is your understanding of the experience of mental illness?

What influences have affected your perceptions of mental illness?

How does it feel to be 'living the experience' of mental illness?

Do you think your experiences are typical of the mentally ill experience?

What does it mean to you to be mentally ill?

How does it feel to be mentally ill?

Have your feelings or experiences changed at any stage since you were diagnosed mentally ill? How?

Can you describe any strategies that you use to help you through the experience of being mentally ill?