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**Author**

Seloilwe, Esther Salang

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# FAMILY PSYCHIATRIC CAREGIVING IN BOTSWANA: EXPERIENCES, DEMANDS, AND SOCIAL SUPPORT

by

**Esther Salang Seloilwe**

DISSERTATION

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# FAMILY PSYCHIATRIC CAREGIVING IN BOTSWANA: EXPERIENCES, DEMANDS, AND SOCIAL SUPPORT

# DEDICATION

To my late father Timothy and my mother Matlhodi Mahlanza
For being my parents, for giving me a beginning, and for teaching me to value hard work

To my late aunt Esther Kabila
For envisioning me

To my husband Gaoralalwe
For continuing and for standing by me always

To my son Mothusi and my nephew Tebogo
For the joy and sacrifice

To my uncle Jonathan and aunt Marie Mahlanza and children
For your unwavering support and constant encouragement

To all those who suffer from mental illness and their families
For sharing knowledge

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## ABSTRACT

# FAMILY PSYCHIATRIC CAREGIVING IN BOTSWANA: EXPERIENCES, DEMANDS, AND SOCIAL SUPPORT

ESTHER SALANG SELOILWE, RN, RM, Ph.D.

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This study used a grounded theory design to investigate family caregiving of psychiatric patients in Botswana. A convenience sample of thirty (N=30) caregivers (26 females and 4 males; 16 urban and 14 rural) participated in in-depth interviews concerning experiences, demands, and social support of family caregivers for the mentally ill persons living at home. In addition, four family group interviews including men and women were conducted to explore the concept of multiple caregiving situations.

Data analysis involved open and axial coding and grouping like data to form core categories through constant comparison and saturating theme categories. Interviews revealed a myriad of experiences and problems that family caregivers encountered in providing care for their mentally ill relatives. The experiences were characterized by shock, persistent sadness, sorrow, anguish, suffering, and struggling. The caregivers constantly grieved for their mentally ill relatives whose failure to recover led to multiple searches for treatment from both traditional and western healers. Mental illness was perceived as a unidimensional entity with multidimensional causality. It was believed to affect the head or mind and could result as a punishment from God, witchcraft, disobeying ancestors, and disregarding taboos.

The caregiving situation was perceived as difficult and burdensome due to caregivers' lack of control over the situation and lack of resources. The families expressed dire need for both material and informational support.

Caregiving situations were collective or multiple in nature. Members of the family shared care cooperatively and through consultation. The caregiving situation follows an undulating trajectory because it is unpredictable, erratic, and uncertain. It is dependent and influenced by various factors such as the ill person's condition, relationships, interactions, and resources in the community environment.

The complexity of the caregiving situation is captured by the spider web metaphor, depicting the extent, magnitude, and intensity of the caregiving demands. The web expresses the entangling , enclosing, engulfing, and trapping nature of the situation for caregivers. The metaphor highlights the difficulty of escaping from the caregiving situation. Families negotiate the caregiving situation to overcome the problems and demands placed on them by utilizing coping strategies of accepting, negotiating, accommodating, and manipulating.

The need to support the families is critical for satisfactory and efficient provision of care for their mentally ill relatives. Support impediments were highlighted and implications for community mental health nursing and policy development advanced.

Linda Chafetz

Linda Chafetz, RN, DNSc.
Chair of Dissertation Committee

Esther Salang Seloilwe, RN, RM, MSc.

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# CHAPTER I: INTRODUCTION AND STATEMENT OF THE PROBLEM

As the locus of care for persons with mental illness shifts from hospitals to communities, families have become increasingly pivotal or central to care of their mentally ill relatives. This shift of care also creates demands for the families to provide care and heightens the importance of understanding the impact of such situations on the families of persons with mental illness. Hatfield and Lefley (1987) noted that health professionals are now required to work with families in new and different ways in order to understand their predicament. The care of the patient in the community necessitates collaboration between the two parties; but the families do not always get a "fair deal" and they become frustrated, overburdened, and exhausted by the care of their relatives (Hatfield & Lefley, 1987). This study focused on the experiences of families in providing care to their mentally ill relatives at home and the kind of support available to them to enable them to cope with the demands of caregiving.

Mental health professionals need to be concerned about providing support for these families. Some prior research indicates that many of these family caregivers lack understanding and skills about mental illness. The families also lack professional support (Hatfield, 1979; Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991; Thompson & Doll, 1982) and community support (Chafetz & Barnes, 1989). The families of the mentally ill in Botswana live with and assume total responsibility for their ill relatives and yet little is still known about their experiences, needs, the available and utilization of resources, and their support systems.

Family caregivers in Botswana live with their mentally ill relatives full-time. Literature on family caregiver burden suggests that they contend with many demands and situation specific stresses associated with living with and providing care for their mentally ill relatives. Special problems associated with psychiatric caregiving include understanding the illness, coping with the disturbing and disruptive behaviors, making long term commitments to provision of material resources such as food, clothing, and shelter for the mentally ill. While these universal patterns are known, it is unknown how families in Botswana differentially experience and meet their caregiver demands. It is also unknown how experiences and demands about the caregiving situation impact on the health outcomes of both the caregiver and the recipient of care.

In addition, it is unknown how multiple caregiving impacts caregiving situations. To date the focus of research on caregiving has been on the primary caregivers (parents) with little attention to multiple caregiving situations involving siblings, spouses, nieces and nephews, and children of the mentally ill, especially if these other groups live with the mentally ill. This is particularly important in the case of Botswana because families are extended and thus consist of multiple caregivers. It is important to understand the roles and contributions of each member of the family and how these impact on the caregiving situation. Such understandings may also clarify the role gender plays in multiple caregiving. Males have been studied only as solitary caregivers and no knowledge exists of male contribution to multiple family caregiving. Finally, caregiving literature in Botswana is very scant. It is important to develop the knowledge base of family caregiving in this region.

## Purpose of the Study

The purpose of this study was twofold. The first was to understand and describe the caregiving situation of families of relatives with mental illness in Botswana from the perspective of the families themselves. It is believed that this information will guide clinical practice and assist health providers in the development of appropriate and relevant interventions for the families of the mentally ill. The second purpose was to contribute to theory development about caregiving of the mentally ill in Botswana grounded in the ways families conceptualize their own caregiving situations.

## Background of the Study

Family caregiving always exists within a complex context of historical, social, economic, political, and cultural factors. In Botswana, the situation is further compounded by the effects of colonialism. Colonialism has had a very strong impact on the health care of Batswana in general. The institutions that existed during the colonial period were not meant for the native people but for the colonial masters. Therefore, the admission of the native mentally ill to these institutions was inconceivable.

In order to study the phenomenon of family caregiving for the mentally ill in the community in Botswana, the process of deinstitutionalization and its influences will be explored. Specifically, the discussion will focus on the major antecedents of the deintitutionalization movement; its successes, failures, and consequences.

## Care of the Mentally Ill in Botswana: A History

Caregiving of the mentally ill by the family is not a new concept. Family caregiving is actually as old as mankind. Perhaps, what is new is the recognition by the health providers of the important role the families play in the care of their mentally ill relatives. All the world over, the care of the mentally ill has been influenced by three distinct historical epochs: 1) pre-asylum period; 2) asylum period; 3) post asylum years. Attention will be paid to these historical periods in the discussion of caregiving of the mentally ill.

## Pre-asylum Period

This period is marked by the families being the sole caregivers responsible for their mentally ill relatives. The mentally ill population was categorized into three: 1) "dangerous lunatics" who were sent to hospitals specifically for blacks outside Botswana in South Africa and Zimbabwe ; 2) "lunatics who were merely destructive to property and were a serious nuisance" who could be kept in the local prisons; and 3) the "harmless imbeciles" who were cared for at home by the relatives and the chiefs (Ben-Tovin, 1987).

Those mentally ill who could not be accommodated in the institutions in these neighboring countries were put in prisons (Dyke, 1933). Those sent to other countries often lost contact with their relatives. Admission of the mentally in prisons was seen as inhumane by such people as Chief Tshekedi, one of the most influential chiefs during the colonial period and Dyke who initially tried in vain to convince the colonial government to build an institution for the mentally ill persons. The situation of the mentally ill was too compelling for Chief Tshekedi to ignore. He pushed for a mental hospital to be build within the country (Unpublished Minutes of the African Advisory Council, 1944).

## The Asylum Years: 1946 - 1978

The first mental health hospital in Botswana opened in 1938 (Ben-Tovin, 1987) and is located in the southern part of the country (refer to figure 1). However, many of the mentally ill were excluded from admission. A year later, after its opening, the new mental hospital began to suffer serious overcrowding, with admissions going up to more than five times the number of available beds (District Commissioners Conference 1947, unpublished proceedings, Gaberone: National Archives; Lobatse Mental Health Annual Report, 1984; Mambwe, 1989).

Further, though this mental hospital was opened, it was operated as annex of the nearby Athlone General Hospital, without trained staff. This meant that most severely disturbed patients continued to be kept in prisons until such time that qualified staff were obtained (Moagi, 1977). It was clear that this alternative confinement of the mentally ill was not going to be successful. The overcrowding and undesirable living conditions in this hospital prompted developments of alternative programs for care of the mentally ill.

## The Post Asylum Years: 1978 to Present

This period often referred to as the community years marked the introduction of the community mental health movement in order to re-integrate the mentally ill into the community (Ministry of Health Annual Report, 1984). In Botswana, as in many other countries, the impetus for community mental health care was, in part, a result of the advent of chemotherapy and consumer involvement. The intent of this movement was to provide humane and effective care for the mentally ill. Bachrach (1978) points out that community mental health care was based on a prevailing ideology with three core beliefs: 1) communities were "good" for the mentally ill, 2) communities were willing to assume responsibility in care, and 3) functions that could be performed in the hospitals could be performed better in the community.

The optimism that prevailed about deinstitutionalization was short-lived in numerous national contexts. In the U.S. and elsewhere, numerous factors stifled the successes of this movement. Even in countries with a well articulated program for community mental health. The main inhibiting factor was the meager allocation of resources to mental health services. In Botswana, as in other developing countries, the provision of mental health services has not been a priority of national public health policy. The primary focus has been on more life threatening health problems such as maternal and child health and communicable diseases. Furthermore, the lack of initial planning for community mental health meant that there were no vocational and rehabilitative services in place for proper integration of the mentally ill into the community. Families were also not adequately assessed to determine their capabilities to handle the task of caregiving. Compounding the situation further were logistic and environmental problems. In Botswana, there are gross shortages of mental health workers and in spite of great efforts, services only reached 10% coverage of the population (Mambwe, 1989). The ultimate result was a relegation of community mental health care onto the families and the community who were ill-prepared to deal with this responsibility and the demands of caregiving, especially where alternative institutions and programs for the mentally ill persons are non-existent.

Currently in Botswana, 100% of the discharged patients return to their families. Botswana is a very large country with a scattered population and inadequate road infrastructure. This impedes the out-reach programs, thus placing great limitations on community services. Consequently, families are left alone in the midst of these difficult situations with resultant overburden.

## Significance of the Study

This study targets the following contributions to nursing knowledge in Botswana:

First, an understanding of the experiences of the families of the mentally ill in Botswana will provide additional unique information on their needs. Although some research has been conducted psychiatric caregivers in western countries, a study of this nature has not been conducted in Botswana. Furthermore, research to date has obtained data on white middle class populations with the exclusion of other ethnic groups. Extending this type of research to other populations such caregivers situations in Botswana is critical to provide the basis for the development of appropriate intervention strategies in the community.

Secondly, Botswana as a developing country has continued to utilize research information developed in foreign cultures especially the western world. The need to generate a knowledge base appropriate and relevant for addressing the needs and aspirations of Batswana is not only immediate but imperative and critical. Inherent in the conceptualization of caregiver experiences, burden, and social support are cultural orientations. The culture of a people determines the way people look at situations, their actions, and the meanings they attach to these situations. The way Batswana conceptualize their caregiving situation is unknown. This study will enhance this understanding.

Although attempts have been made to define and measure such concepts as caregiver burden, experiences, and support in the western literature, the applicability of such definitions, conceptualizations, and measurement of such concepts in a Setswana culture remains questionable. It is imperative for research knowledge to be conducted in cultural contexts in which it will be applied in order to understand the meanings other cultures have for particular phenomena. Vega and Rumbaut (1992) argue that the creation of culturally relevant measures requires knowledge about that particular cultural group such as the socio-demographics, language, customs, beliefs, and values. The knowledge base that exists has not taken this fact into consideration. This heightens the importance and the need to conduct this study in Botswana.

Thirdly, it is hoped that the study will bring about change beyond the experiences and support needs of family caregivers and beyond the level of scholarly pursuit. It should contribute to economic, political, and social changes at the local and national levels for the betterment of the quality of care for the mentally ill in Botswana.

## The Country, Population, Social Services and Programs

### The Country

Botswana is a landlocked country with an area of 570,000 square kilometers and lies in the Southern African plateau bounded by South Africa in the east and south, Namibia and Caprivi Strip in the west, Zambia and Zimbabwe in the north (see to figure: 1). It is almost the size of Texas in the US. or France in Europe.

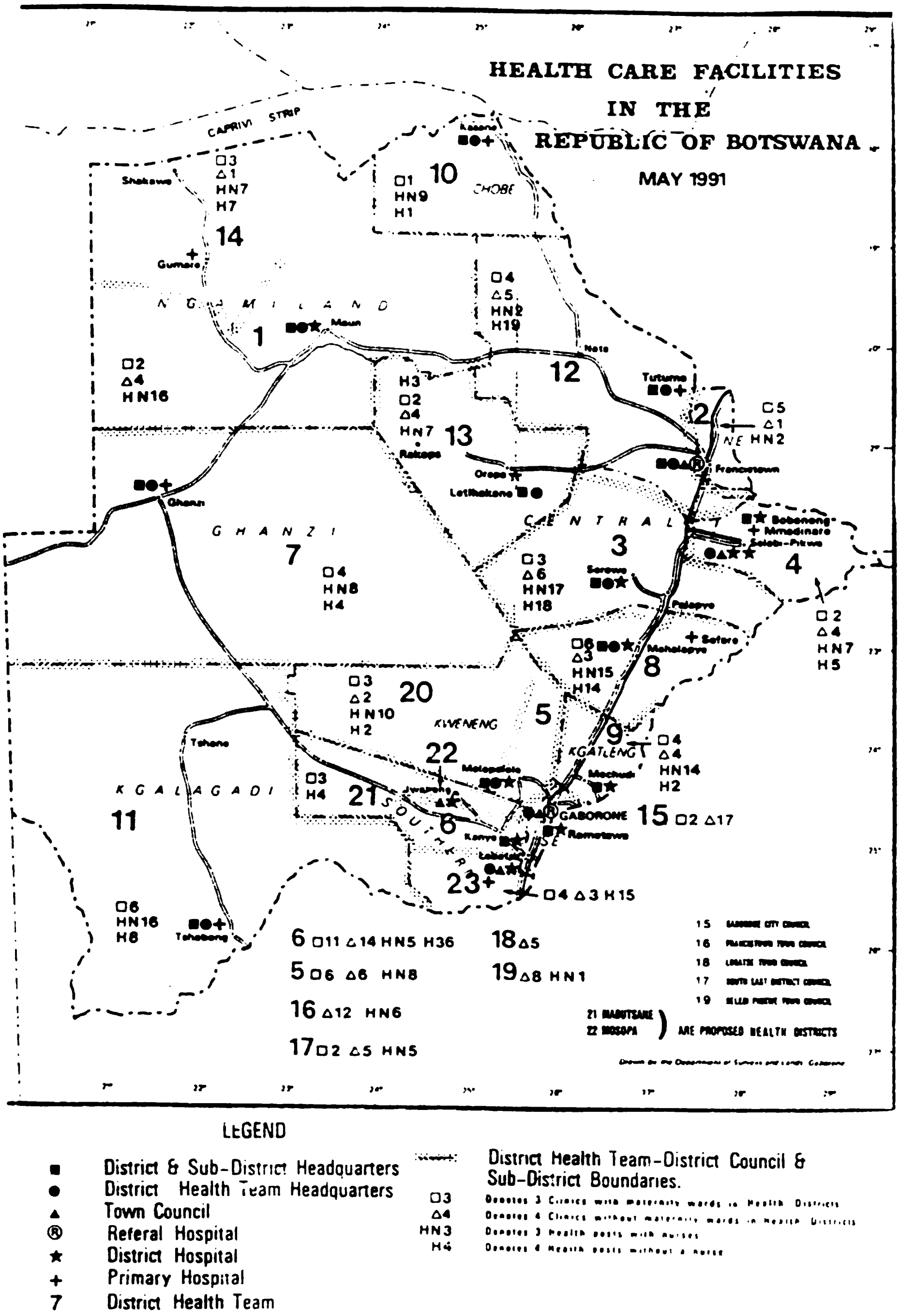
The climate is continental and semi-arid, with an average annual rainfall of 45 cm. The rainfall is erratic and unevenly distributed, ranging from 30 cm in the south west to 70 cm in the north west. The country lacks perennial surface water except in the north west.

The mean maximum temperatures vary according to region but temperatures seldom rise above 38 degrees centigrade. About 84% of the surface land is covered with Kgalagadi sand which supports a low Savannah type of vegetation. The land suitable for cultivation is only 5%. The main crop is sorghum, but maize, millet, beans, and other crops are also grown.

### The Population

The availability of water is the main influence on the pattern of settlement in Botswana. About 80% of the population lives in the catchment area of the Limpopo river in the eastern part of the country, where there are reasonably fertile tropical soils and where the rainfall is sufficient to permit arable agriculture (see figure 1). The results of the 1991 census showed the population to be 1,327,638 (CSO, Population & Housing Census, 1991). This is an increase of 63% since 1971. The growth rate of the population is very high, indicating that Botswana has a predominantly young population. Almost 48% of the population is 15 years and under (National Development Plan 7, 1991 - 1997).

Figure 1: The Map of Botswana Showing Health Care Facilities



## Political and Legal Organization

Botswana adopted a constitution in September 1966 that provides for a republican form of government headed by a President, with three main organs of government: the legislature, the executive, and the judiciary. The legislature comprises of the national assembly and act in consultation on tribal matters with the house of chiefs. The executive consists of the cabinet headed by the president and it is responsible for initiating, directing, and implementing national policy. The judiciary administers and interprets the law of the land and it is dependent on both the assembly and the executive.

## Economic Developments

The British colonial rule left hardly any economic developments in Botswana. There was a complete disregard for education, health, communications, manpower training, and water development (Kupe, 1993). British occupation in Botswana was mainly for strategic reasons and regular supply of migrant labor to work in the South African gold and diamond mines. At independence in 1966, Botswana was one of the poorest developing countries. The poverty level was escalated by serious droughts that lasted seven years prior to independence (Kupe, 1993). The mining industry has had the most dramatic improvement on the economy and other sectors (National Development Plan, 1991 - 1997). The rapid expansion of the cattle industry and beef exports to European Economic countries also raised the standards of living in Botswana. Despite the improved standard of living revealed by the socio-economic indicators and socio-demographics such as creation of jobs, increased literacy, better housing, reduced infant mortality, and increased life expectancy, there is still a significant population that lives in poverty. The Rural Distribution Survey (RIDS, 1975-76; CSO, 1976) indicated that about 45% of the rural households had an income below the poverty datum line (PDL). The urban PDL studies (1970) estimated about 36% to 47% of the urban population was living below the poverty datum line. Several rural income distribution studies have had converging results on the poverty status of households.

## The Health Care System

Two health care systems run concurrently in Botswana: the western and the traditional health care. Every Motswana has access to the traditional health care and not everybody has access to the western health care. The selection of health care is influenced by the beliefs, customs, and values of the people. The usual practice is that people exhaust the traditional health care services first before consulting the western health care, especially those suffering from illnesses that are still not understood such as mental illness. It is for these reasons that health care providers take into cognizance the operations of these systems and fully comprehend the belief system of the people they deal with so as to strike a balance between the two health care systems.

### The Western Health Care

At independence, Botswana inherited a largely curative, hospital-based health care delivery system from the British, with the majority of the population without access to any services at all (Ministry of Health Annual Report, 1979). Government was therefore challenged to provide health care for majority of the people. This necessitated the building of basic health facilities throughout the country (see figure 1). The main objectives were to strengthen the primary health care services, to equitably distribute them for all people with more emphasis on the rural areas, and to improve hospitals to ensure adequate referral services. The emphasis of health policy was directed towards the prevention of more life threatening health problems such as maternal and child health and combating of communicable disease such as childhood diseases, Tuberculosis, Malaria, to name a few. The trend of the health policy however, has not changed significantly since its inception.

Health care facilities are organized at different levels of sophistication and coverage (Ministry of Health Annual Report, 1979). The health facilities are provided based on the population of that particular area. At the lowest level are the mobile stops or outreach which are generally done either under a tree or at school. Then follows the health post, clinics, primary hospitals, district hospital, and lastly the referral hospitals.

According to the National Development Plan 7 of 1991-97, the distance and the size of the population guided infrastructure development. A 15 kilometer radius and a population of 500 were the requisite criteria (Sebina, 1980). It is currently estimated that 86% of the population within the 15 km and 73% within 8 km walking distance has some access to a health facility (MFDP, 1991).

There is a single mental hospital in the southern part of the country. Attached to the district hospitals are psychiatric outpatient clinics run by psychiatric nurses and a psychiatrist who visits them on monthly basis. A psychiatric clinic serves a particular catchment area which is usually very big, in terms of the population and area, a factor that negatively impacts the quality of services provided (Mambwe, 1989).

The provision of basic services in Botswana was long conceptualized before the Alma Ata Declaration. However, in 1978 the Primary Health Care (PHC) was adopted as a meaningful strategy in providing the health care services that are affordable, accessible, and equitably distributed. PHC reflects a philosophy of citizen involvement and collaboration. Effective collaboration between informal and formal care systems depends on negotiated models of cooperative caring (Thorne & Robinson, 1988) in which professionals and people respect each other's knowledge, expertise, and strengths and resources that each other can offer (Marsh, 1992).

### Psychiatric Morbidity in Botswana

The classification of mental disorders in Botswana conforms to the International Classification of Disease (ICD 9). Schizophrenia, epilepsy, alcohol related problems, affective disorders, organic brain syndrome, and neurosis are the top six causes of psychiatric morbidity (see Table 1). The presentation and prognosis of schizophrenia in Botswana do not appear to be any different from that reported from other the parts of the world. Basically, it is an illness of late adolescence to early adulthood with many re-admissions and propensity to chronicity (Mental Health Program Action Plan Ministry of Health, 1992-97, MHPAP).

Table: 1 Most Common Causes of Psychiatric Morbidity (Source: MHPAP, 1992-97, Ministry of Health, Botswana).

| Diagnosis ICD 9 | 1989 | 1990 | | 1991 | |
|---|---|---|---|---|---|
| | OPD | OPD | AMSIN | OPD | ADMSI |
| | n=10242 | n=12516 | n=1099 | n=9365 | n=1088 |
| Schizophrenia | 36.6% | 35% | 34% | 37% | 35% |
| Epilepsy | 24.7% | 11% | 6% | 23% | 6% |
| Alcohol Related Problems | 9.8% | 17% | 20% | 10% | 17% |
| Affective Disorders | 7.5% | 13% | 13% | 10% | 12.5% |
| Organic Brain syndrome | 9.35 | 6% | 6% | 5% | 5% |
| Neurosis | 7.3% | 9% | 9% | 9% | 3.1% |
| Total | 94% | 80% | 91% | 79% | 93% |

## Traditional Health Care

According to the traditional Tswana society philosophy, illness, death, and misfortune are never accepted as natural occurrences; they are attributed to the supernatural intervention of some external agent (Kupe, 1993). Such agents could be: 1) ancestral spirits (*badimo),* who are the regarded as the guardians of familial and tribal morality, and can sanction punishment for any deviation from or violation of familial and tribal norms with illness and misfortune. 2) Supreme God (*Modimo*) who is the creator of the universe and controller of rainfall. He inflicts punishment for deviation from his wishes for the tribe by sending drought, thunder, lightning, disease, and death. 3) Sorcerers (*baloi*) who cause illnesses and misfortunes through witchcraft or manipulation of roots and herbs in such a way that illness, death, and misfortune would befall the individual or his properties (Kupe, 1993).

Treatment of illnesses will therefore, depend on what is believed to have caused it. If the illness is believed to be caused by ancestral spirits then certain rituals such as prayers or offerings are held within the family to appease the spirits. If the illness is caused by the sorcerers then a traditional medicine man is consulted to counteract the sorcery with his powerful roots and herbs.

They are various traditional healers with different treatment modalities. They include the herbalists who mainly used herbs and roots, bone casters who diagnose through throwing bones and determine the treatment, and the spiritual healers and the prophets who mainly pray and cleanse the body through purging and *sewasho* (giving somebody salty water to drink and causing them to vomit). The focus of treatment modalities in the traditional health care system often targets groups or families rather than individuals, especially in situations were the rituals are performed to appease the ancestral spirits.

The beliefs about the causes of illnesses are deeply entrenched in the religion of the people and the religion of any people constitute the life and hope of such people (Kupe, 1993). Understanding the belief system of people will consequently assist in addressing their problems in a more specific, relevant, and appropriate way. For this reason traditional healers are incorporated into the national health care system although communication between the traditional and the western health care needs improvement. There needs to be more sharing of information, ideas, and practices.

## Comparison of the Traditional and Western Health Care

This section offers a brief comparison between the traditional and western health care systems operative in Botswana. The comparison is based on psychiatric morbidity. However, most traditional explanations and treatment of illnesses do not differ. The same medicine, herb or ritual may be used to treat a wide range of health problems.

Table 2: Comparison of the traditional and western health care systems

| Criterion | Traditional | Western |
|---|---|---|
| Method of acquisition | Family lineage and cultural institutions | Medical and Nursing schools |
| Practice setting | Community based | Institution and community |
| Accessibility | Readily accessible | Accessible |
| Affordability | Costly and expensive | Liberalized socialized and very affordable |
| Utility rate | Very much utilized | Utilized |

| | | |
|---|---|---|
| Explanations of causes of disease | Witchcraft, sorcery, violation of taboo, disobeying of ancestors | Biological, behavioral, heredity, chemical etc. |
| Beliefs about illness | Culturally based | Scientifically based |
| View of illness and treatment focus | Family or group | Individual |
| Medications | Herbs, powerful roots, ritual offerings, prayers, body cleansing by purging and vomiting | Processed chemical substances e.g., drugs, vocational, rehabilitation |
| Types of doctors | Herbalist, bone casters, spiritual, sangomas | Psychiatrists, nurses, social workers, occupational therapists |
| Openness | Very secretive and private, no questioning encourages conformity | Open, allows questioning |
| Times of consultations | Usually at night or early morning | Any time of the day |

## Social Services Provision

### Departments that Participate in Care of the Mentally Ill

Apart from the health care systems outlined above, there are several social services that participate in the delivery of community mental services in Botswana. These include but are not limited to the police, prisons, district commissioner and social workers. These departments mostly assist during crises situations, when a mentally ill person has relapsed and requiring rehospitalization. The department are usually responsive by providing transportation to the main mental hospital in Lobatse. The prison and police cells are sometimes used temporarily to admit these patients in some parts of the country where there are no hospitals. However, admission of the mentally ill in such places is restrictive to 48 hours after which the law requires that the ill person should have be transferred to the mental hospital.

### Social Welfare Scheme

The social welfare schemes that are currently operative in the country have not greatly benefited mentally ill persons. These are mainly in the form of food rations or food grants. The system of food grant was established in the 1980's for the destitutes who were defined as people who are unable to provide for their basic needs These people get an equivalent of P100 ($30) worth of food every month. The food rations include the following items: 12.5 kg mealie meal (corn meal), 10 kg sorghum meal (bopi ba mabele), 5 kg bread flour, 2 kg sugar, 2 kg samp, beans, 750 ml cooking oil, salt, tea, coffee, milk, 500 mg washing powder, 2 cakes bath soap, baking powder, body lotion, and spices.

This system seems to work poorly because it has many discrepancies. The criteria used to assess beneficiaries are not well defined and exclude a substantial number of disadvantaged and very impoverished people. Some potential beneficiaries become impatient with the assessment process and lose interest, failing to follow up. Hence they are denied the benefits.

The other most recent scheme is the old age pension scheme (OAP). The criteria is basically age and not means. To qualify one has to be 65 years and above. It is estimated that the population of the elderly has increased and thus the sustainability of this scheme remains questionable. OAP too excludes the mentally ill persons.

## Provision of Water

The premise of water development policy was to provide clean, desirable, reliable, and proximate water to the population (SIAPAC-Africa, 1990). The thrust of the policy was provide stand pipes in rural areas and low income areas in urban places. Most of the urban areas are provided with piped water. According to SIAPAC-Africa (1990), households with access to clean water increased from 45% in 1975 to 90% in 1991. By 1991, 100% of households in urban areas and 55% in rural areas had access to piped water. However, only 41% of urban and 9% of rural households had piped indoor water.

## Sanitation

Sanitation presents a major problem for Botswana. According to the 1991 census, 14% of households had flushing toilets and 37% had pit latrines. The Income Expenditure Survey (CSO, 1995) suggested that provisions of sanitation were still inadequate and basic.

## Definition of Setswana Concepts and Terms

This section offers definitions of some Setswana concepts and terms that have been commonly used in this dissertation.

- Botswana refers to the country where the study was conducted
- Batswana (plural) refer to the people of Botswana, Motswana is singular
- Setswana refers to the language spoken in Botswana
- Tswana may refer either to the language spoken by Batswana or the people of Botswana.
- Gaborone is the capital city of Botswana which was the urban setting
- Molepolole a village west of Gaborone and was the rural setting

  Lobatse is a town 70 km south of Gaborone where the mental hospital is situated

- Badimo (Gods) (plural) refer to ancestral spirits, Modimo (God) is singular
- Dagga refers to marijuana
- Kgotla is the a traditional institutions which runs the affairs of a clan or village

## Overview of the Dissertation

In chapter one the study problem, its background, purpose, significance have been presented. The macro setting, which is the country, its population, socio-political organizations, and social services operative in Botswana are described. The antecedents factors that have led to the development and evolution of community mental health services in Botswana were outlined.

Chapter Two outlines the conceptual framework that served as a template for the study. Also, a critical review of relevant studies on the subject done in Botswana, Southern Africa, United States, and Britain is provided. Their relevance, inadequacies, and future trends in research are outlined.

Chapter Three describes the methodology that was utilized to conduct this study. Methodological issues and concerns that arose during the research process are also described.

Chapter four presents the study findings of individual interview data, family group interviews, and field observations. Chapter five discusses the interpretations of the findings.

Lastly, chapter six presents the conclusion and implications. The study contributions and limitations are also given. Implications for nursing theory, nursing practice, nursing education, nursing research, and policy development are described.

# CHAPTER II: REVIEW OF LITERATURE AND CONCEPTUAL FRAMEWORK

Mental illness is a significant problem that affects the patients, their families, and the broader community (Biegel, Sales, & Schulz, 1991). This review of literature attempts to explore the effects of mental illness on the family as well as the interventions that were instituted to enable the families to cope. The bulk of studies reviewed were conducted in the western countries such as the United States of America, Great Britain, and Canada because literature pertaining to family caregiving of the mentally ill is still very scant in Botswana. The review mainly evaluated the designs, methodologies, theories, and instruments utilized in these studies with a view to assessing the applicability of these findings in non-western countries and the extent to which methodologies utilized could be useful in guiding the proposed study of family caregiving in Botswana.

The literature review was divided according to the following categories: 1) caregiver burden; 2) caregiver support; 3) patient support; 4) intervention modalities. Although the focus of the study is on family caregivers, it is believed that this literature will enhance the understanding of the caregiver situation; what is known, unknown, the gaps, and the inadequacies that exist. In addition, the literature will guide future research in this field.

The questions considered in the review of this literature included: 1) What has been the extent of burden experienced by the families in caregiving of their mentally ill relatives? 2) How did this burden manifest itself? 3) What effect did this have on the psychosocial status of the family? 4) What kinds of interventions were instituted to assist the families to cope? 5) What did the families identify as interventions that could help them? 6) What significant gaps or inadequacies exist in this body of literature? 7) How was this body of research applicable in other settings? 8) What was the utility of this body of research in other cultural settings, specifically Botswana? In reviewing the literature, theories, methodologies and instruments that were utilized were considered.

## Caregiver Burden

The review of literature focused mainly selected studies done in the last two decades. Early studies of caregiver burden had their main objective as finding ways to improve the family caregiver situation in order to facilitate the community reintegration of the mentally ill. In a seminal work, Grad and Sainsbury (1963) examined the effects on the families of home care, as compared to hospitalization of the mentally ill. Authors interviewed every second patient and family member in Chichester (N = 271) and every fourth patient and family member in Salisbury (N = 139). Results indicated that over 61% of families had suffered some hardships at home because of the patient's illness, hardships being severe in 20% of the families. The authors then examined the effects of community based services on burden levels of family members, with burden measured before and one month after admission to treatment. There were no significant statistical differences found between the two types of treatment. These findings illustrate the long lived and historical failure of mental health systems in providing follow up services for former patients and their families.

Since this study, almost two decades later, an upsurge of research emerged in the area of caregiver burden. Thompson and Doll (1982) examined the emotional and social costs of those families charged with the burden of caregiving for their mentally ill relatives ( N= 125). Subjective burden was measured by the Index of Family Members' Embarrassment. Affective dimensions of family were assessed by a modified form of Incomplete

Sentence Blank (ISB). Objective burden was defined in terms of every day life and these indicators were obtained: financial burden, role strain and interruptions in the family's normal way of life.

Results indicated that 73% of the families were adversely affected in one or more ways attesting to the painful experiences that families go through. This accentuates the vulnerability and susceptibility of families to burden. Findings also indicated that families experience some kind of burden to somewhat different degree and do have different experiences. This is suggestive that interventions should target specific problems that families have. It is envisaged that the levels of burden will differ from one situation to the next, thus implying that burden is context specific.

A shift is noticed around the mid and late 1980's when research focused on a variety of problems to ascertain the extent of burden such as health, social participation, behavioral problems, and financial resources. George and Gwyther (1986) examined the well-being of family caregivers of older memory- impaired adults in four dimensions: physical health, mental health, financial resources, and social participation. A non-random voluntary sample ($N = 510$) was obtained through mailing list of Family Support Program (FSP) which is a statewide technical assistance program for the informal caregivers of older persons suffering from Alzheimer's Disease. The sample was 97% white, 2% black, and 1% American Indian. The well-being was measured by multiple indicators from well-being dimensions . Physical health was measured by the number of visits to the physician. Mental health was measured by using four indicators: a checklist of psychiatric symptoms, a measure of affect, a single-item measure of life satisfaction and absence versus presence of psychotropic drug use. Financial resources were measured by two indicators: household income which is a relatively objective indicator of financial status; and a multi-item scale measuring respondents' subjective assessments of their economic well-being. Analysis of variance was used to determine whether the differences across groups were statistically significant.

Results found spouses caregivers to be significantly different than the other two groups. Reported more doctor's visits ($p < .05$), poorer self-rated health ($p < .01$), and exhibited lower levels of well-being. Caregivers who reside with their ill relatives were most likely to use psychotropic drugs ($p < .05$) reported the highest level of stress symptoms ($p < .01$), lowest affect and life satisfaction, and lowest levels of social participation. The findings suggest that caregiver burden is experienced primarily in the areas of mental health.

The results provide an understanding of the effects of caregiving and they elicit important conditions that caregivers are at risk and are vulnerable to discomfort emotionally. There was also evidence of psychotropic drug use in this sample indicating levels of distress that often accompany caregiving responsibilities. There are implications that interventions targeted for caregivers are clearly needed. However, the results of this study cannot be generalized because the sample was non-random , mostly white, and middle class. Studies which include other groups are needed because they might be experiencing different problems.

Gubman, Tessler, and Willis (1987) descriptively contrasted factors affecting complaints in family households with factors leading to complaints in the residential alternatives. A subsample of 432 individuals with chronic mental disorders participated in the study. However, it is not clear how this sample was obtained. Two categories of variables were used to capture passive violations of prescriptive rules: household living skills and social activities. The items for house hold living skills were maintains personal hygiene, diet, performs household chores, and manages finances. The types of social activities were recreational activities, having a daytime schedule, and socializing with friends. The behavioral problems reported by case managers constituted the final group of variables. A hierarchical regression was used. Behavioral problems such as temper tantrums, bizarre behavior, and destruction of property, were found to be the best predictors of household complaints than any other variables (22.7%). It was found that violation of rules was significant in triggering complaints. The study differentiated kinship from co-residence and found that the problems were similar (11%).

In a grounded theory study that sought to understand burden on mothers who care for their chronically mentally ill adult children; Belcher (1988) interviewed 21 respondents from a low income group. Informants were obtained through their mentally ill children admitted and discharged from a hospital acute ward. Mothers reported being physically and mentally exhausted, and appeared trapped by their adult children's behavior. They had very little knowledge about mental illness and they could not explain to their friends what their adult children were suffering from. The neighbors also expressed frustration and anger about the mother's housing a mentally ill adult child. This created a stressful environment for the family. The mothers were asked to rate their health as fair, good, and excellent. At first rating mother thought their health was fairly good. Subsequent follow ups showed a decline in health. Therefore, poor health seems to be the best indicator for burden, a finding that has been seen in other studies.

Although the convenience sample was small, and drawn from low income group, the results are important because they suggest the difficulties that parents of the mentally ill go through. The study corroborates the findings of other studies of the importance of health in predicting caregiver burden (George & Gwyther, 1986). The other strength of this study is that it was a longitudinal design and thus observed effects of caregiving over time.

In an attempt to identify the typologies of burdens of living with depressed relatives, Fadden, Bebbington, & Kuipers (1987), interviewed 24 spouses and rated the answers. Very few had major changes in the routine work because of the relatives' illness, but half found their work to be strenuous as a result of their responsibilities towards the mentally ill relative. The family members experienced reduction in the number of social activities due the relative's illness. Constriction of social activities was particularly marked when a patient was a male. Although the study provides important descriptions of the problems faced by the those living with relatives suffering from persistent depressive disorders, the results cannot be generalized due the convenience sample.

Robinson (1989) investigated the relationship of caregiver health, past marital adjustment, and received social support to depression. A sample of 78 wives who served as primary caregivers to husbands with irreversible memory impairment were recruited. Recruitment was done through chapters of the Alzheimer's disease and related disorder associations, home health agencies churches, and senior centers. The sample composed of only two blacks. The Louisville Health Scale which has an internal consistency reliability with alpha coefficients of .82 to .89 was used to collect the data concerning the well-being and functional health. The Inventory of Socially Supportive Behavior (ISSB) Barrera et al., (1981) was used to measure social support which was defined as various forms of aid and assistance supplied by the family members, friends, neighbors, and others (Caplan, 1974). Depression was measured by the Epidemiological Studies Depression Scale(CES-D)

The results indicated that the caregivers felt some or little depression. The hypothesis that a negative relationship exists between social support and depression was not supported. There was a significant negative relationship between past marital adjustment and depression (r= - .33, p <.003). Caregiver health was seen as the best predictor of depression (r = -.54, p < .001). Caregivers with positive attitudes toward schizophrenia reported significantly less depression. Caregivers of spouses felt that caregiving was their responsibility and they should be able to do it without assistance. A hierarchical multiple regression analysis was done and health accounted for 40% of the variance in predicting depression, it has to be considered seriously in the study of caregiver burden.

This study has yielded important findings indicating the fact that attention should be paid to health as variable in prediction of caregiver distress. However, the sample was small and non-random; thus generalizability may be limited. The strengths of this study include its basis on Kahn and Antonucci's fitness model and its use of stepwise regression to consider multiple predictors of depression among caregivers of the mentally impaired elderly. Although the recruitment of the subjects was widely advertised to capture a wide and diverse population, future studies should include other ethnic groups.

In a prospective design, Raj et al., (1991) studied 60 Indian families to evaluate the social burden they experienced as they cared for their mentally ill relatives. Burden was measured by the an interview schedule developed specifically for this study which included a wide range of the categories of burden. There were no significant relationships between severity of illness and subjective burden for those who viewed their mentally ill relatives as having positive symptoms. However, those who viewed the symptoms as negative showed a statistically significant correlation between the severity of illness and subjective burden scores ($r = .81, p < .01$) and objective burden scores ($r = .65, p < .01$). Although the findings indicate very high correlations, they should be interpreted with caution because correlations can be unstable (Glantz & Slinker, 1990). It is worth noting that this study was conducted in a non-western culture, but corroborates the findings of western studies on caregiver burden. This might affirm caregiver burden as a cross-cultural phenomenon.

A comparison of Hispanic daughters (N= 13) and white non-Hispanic daughters (N= 15) who cared for their mothers with suffering from Alzheimer's disease was carried out by Mintzer et al., (1992). Subjects were selected through an evaluation agency. The Dementia Scale and the Center for Epidemiological Studies Depression Scale were used to collect data. Subjects were interviewed to determine the number of community based services they had heard about and the level of utilization of those services.

A chi square analysis revealed that 60% of the caregivers reported symptoms of depression and there were significant differences in the levels of depression between the non-Hispanics and the Hispanics, despite the fact that the Cuban-American Hispanics were more likely to be caring for their patient at home. This study has particular relevance to those situations where patients are cared for at home by their relatives because there are some factors that come into play such as caregiver obligation and availability of multiple caregivers, which have received very little attention in the research literature. These factors need to be studied because they seem to have tremendous influence on the caregiving situation and may seem to delay institutionalization in some cases. The findings of this study were preliminary with a very small, non-random sample, and limited generalizability. A much larger scale study needs to be done with the inclusion of other ethnic groups.

Guberman, Maheu, Maille (1992) explored reasons why women cared for other people. They used open-ended questions and asked about circumstances and contextual elements that were present throughout the process of caring for a member with mental disability. Using snowballing techniques a non-random sample was obtained and composed of two groups of Francophone Quebecois caregivers of adults with mental illness (N = 16) and caregivers of frail elderly with Alzheimer's disease (N= 24). The duration of care ranged from 1 to 21 years.

Those who cared for the mentally ill patients had no choice because there were no community resources for their relatives and they found themselves pressured to take of them. The majority of families using institutions spoke of undue pressure placed on them by health professionals to take their relatives home. The study elicited three factors that led to people to care for their relatives: (1) caregiver factors such as love, need to help, duty, socio-economic dependence, anti-institutional, religious feelings, belief in healing, and family tradition; (2) availability of family, institutional, and community resources, and (3) factors pertaining to the dependent person such as imposition and recipient's health. It is interesting to note that some caregivers have no choices in making decisions about the care of their relatives. The health care system actually puts pressure on the families to assume care. As a result, this can be burdensome on the families. Although the sample was small and non-random, the study elicits important findings that can be useful in sensitizing the health professionals about the contribution they make in overburdening the families to care for their relatives.

Gender bias in caregiving have been identified in the literature because caregivers have been predominantly female. As a result, very little information exists pertaining to the males as caregivers. Harris (1993) conducted a qualitative study of husbands caring for their wives with Alzheimer's disease to gain insight into the complex world of the male caregivers and to identify commonalties and differences. The main aim was to obtain an in-depth understanding of what it is like for a man to take the role of a primary caregiver: his motivation, stresses, coping strategies, support network, and use of services. A non-random and exclusively white sample (N = 15) was obtained. A general interview guide covered a wide range of questions about caregiving.

The findings elicited that husbands experienced social isolation because they had met most of their friends through their wives. Men in the early stages of caregiving were more often in a crisis stage. Caregivers who have been taking care for a long time expressed the least burden. Some men cried when they talked about their wives. Some expressed the need to talk with other men in similar situations. Men felt uncomfortable discussing issues such as sex, personal hygiene of their wives in traditional support groups. Many relied on their clergy for their social support.

This study is important because it elicits the practice implications for the male caregiver. Appropriate interventions for this group need to be specific to their needs and thus may not fall in the mainstream. (For example these men indicated that they would not attend the regular support groups). This group needs to be studied more because they do experience some emotional problems indicated by the fact that some husbands cried during interviews and others expressed a need to talk to someone about their caregiving experiences. The emotional imbalance experience by these men, demonstrates that after all men are not as resilient as they have been purported to be in other studies (Stetz, 1987) and thus need to be assisted in their caregiving roles. The study focused mainly on the husbands. Sons too need to be studied to understand their reaction to caregiving roles. Other groups of men need to be included in these studies in order to identify the role ethnicity, race, and social class play.

In a cross-sectional design, Greenberg et al., (1993) tested the hypothesis that increased levels of stigma, worry, fear, and loss were associated with poorer physical well-being in the parents of persons with mental illness. A voluntary sample ($N = 106$) solicited from the Alliance for the Mentally Ill of 18 states received a questionnaire by mail. The results indicated that subjective burden was negatively related to health and health was negatively related to stigma ($r = .32$, $p < .01$). Therefore, subjective burdens related to stigma and worry remain significant predictors of health status. Also, mothers who reported more objective burden also reported poorer health. The findings of the study suggest the importance of assessing the type of subjective burden or distress being experienced by the family and targeting appropriate interventions to reduce this specific distress. However, the results should be cautiously interpreted because the sample was non-random and drawn from people who were committed to caregiving because they belonged to a Mental Health Alliance. Therefore, generalizability is limited.

Winefield and Harvey (1994) used both quantitative and qualitative methods to investigate the needs of the family caregivers in chronic schizophrenia. A convenience sample of 121 subjects was obtained by recruiting the relatives of persons diagnosed schizophrenia through an outpatient and suburban outreach clinics of two public psychiatric hospitals. Data were gathered about the patient as well as the caregiver using open-ended interview and the Life Skill Profile. Caregivers assessed burden in terms of interference with different areas of their daily lives. The areas of caregivers' lives most frequently affected by the caring task were holidays, social relationships outside the home, and relationships within the family. Spouse caregivers and caregivers of adult children reported higher proportions of patient related stress ($p < .05$) than did other caregivers. Although caregivers preferred their ill relatives to live somewhere under supervision so that they could be under constant watch, 78% of the caregivers preferred that the patient not live with them. While the study elicited important information about the caregiver preferences and what conditions burden them, the method of sample selection limits its generalizability. The study is also biased because caregiver subjects were people who were already successful in maintaining long term relationships with the patient.

Utilizing a grounded theory method, Howard (1994) described the caregiving experiences of mothers of adults children with schizophrenia. Qualitative data were obtained from ten respondents using purposive and theoretical sampling techniques. The interview guide prompted in-depth exploration of retrospective life themes. The data classification tool was designed to promote development of the theme about stages of caregiving. Four stages emerged in the caregiving of children with mental illness: (1) perceiving the problem which ensued when difficulties were encountered; (2) searching for solutions which involved learning about the diagnosis and beginning to understand it; (3) enduring the situation by finding some meaningful support and gaining understanding about the illness; and (4) surviving the experience which was recognizing ways to care for self in the face of profound sorrow and continued caregiving.

This is an excellent grounded theory study which clearly spelled out the decision trail and described the caregiving experience from the perspective of the caregiver. The data are rich and were confirmed with the respondents thus ensuring validity. The study is written in clear terms and it points out the problems caregivers encounter which include suffering, anguish, struggling and perseverance. All these factors drain and place a lot of stress on the caregiver.

The study is helpful not only because it uses the method that is to be used in the proposed study, but because it spells out the what caregivers go through. While this study has more strengths than weaknesses, this research should be extended to other family members whose contributions may be similar or different, and whose perspectives should be known. It is also important to understand perspectives of other socio-economic and ethnic groups in order to have a full understanding of the caregiving roles.

The relationship of professional support, caregiver personal sense of control, and burden were assessed by Reinhard (1994). Caregivers (N= 97) of severely mentally ill were identified by ill relatives and by snowballing techniques. The majority of respondents were white, over the age of 55 years, and married. Caregiver burden was measured by the Burden Assessment Scale devised entirely for this study. The 20 item CES-D was used to measure depression and support was measured by the asking the respondent to rate help received from mental health professionals in 11 clinically relevant supportive areas such as affective and instrumental support. Doctorally prepared nurses reviewed instruments for content validity.

Contrary to previous reports, (George & Gwyther, 1986; Coyne, 1987; Given et al., 1992) no differences were found between caregivers who lived with and apart from their mentally ill relatives. Caregivers in both situations reported similar levels of disruptive behaviors, professional support, personal control, burden, depression, and physical health. Depression was significantly associated with burden ($r = .52$, $p < .01$) among caregivers who lived with their mentally ill relatives.

A hierarchical regression analysis revealed that disruptive behaviors accounted for 23% of the variance in predicting burden. Caregivers who received practical advice about managing behaviors and other caregiving matters reported significantly less objective burden ($r = -.24$, $p < .01$). These results exemplify the importance of professional support in mediating the effects of burden. Although this study yielded such important findings, their generalizability cannot be assumed. However, they underscore the relative importance of professional support in reducing burden and potential usefulness of developing situation specific measures.

In a quasi-experimental design, Clark (1994) investigated the costs associated with severe mental illness and substance abuse. Families of adults with dual disorders ($N = 119$) were compared with a similar group ($n = 127$) of families whose children had no chronic illnesses. Telephone interviews were conducted and parents were to report about the amount of money, goods, and direct care family members gave to the ill person.

The results indicated that parents of adults with dual disorders spent far more than parents of adults without chronic illness ($349.01 and $154.82 per month respectively). The two groups differed significantly in the amount time the families spent providing care for the ill relative. Interestingly income did not exert any influence. Low income and high income families of adults with dual disorder group did not differ significantly in the care they gave to their relatives ($t= - 1.155$, $P < .25$). The results show that adults with mental illness do receive more assistance from their families than adults without chronic illness.

These results should however, be interpreted cautiously because only 3% of the sample were composed of minority groups. Therefore, families from different racial and ethnic groups or other cultures may have different ways of providing assistance. This study attests the assistance needed by the families with mental illnesses. Thus, more research is needed to understand better the role families play in providing material assistance. Better ways of supporting families and of working cooperatively with them for the good of their relative must be explored.

To determine the relative power of behaviors of chronic mentally ill clients, behaviors required of caregivers, and demographic characteristics of both in predicting burden, Jones et al (1995) used a cross-sectional, correlational design and interviewed 189 caregivers. The participants were identified through a community mental service in Ohio. Interviews were conducted by phone about the clients' needs for help in nine areas of grooming, medication, housework, shopping, cooking, providing transportation, managing money, caring for client's children, and managing time and about seven potentially troublesome client behaviors using the family burden questionnaire adapted from a protocol by Tessler. Multiple regression analyses were done to determine the relationships between objective and subjective burden and predictor variable of caregiver and client behavior.

The findings showed that all the 189 caregivers identified some objective burden in six of the nine areas. A small percentage reported some subjective burden in the nine areas at significant levels ($p < .05$ to .001). Those caregivers who lived with clients reported greater objective burden. These results are consistent with previous findings (George & Gwyther, 1986; Coyne, 1987; Given et al., 1992). However, caregivers of female clients suffered less than those of males. Most caregivers were females and clients were males.

This data is invaluable in providing professionals with information to improve the quality of care for clients and their families. The professionals must assist the families to understand the behaviors of the clients and thus decrease burden. While this study demonstrated how client characteristics can influence caregiver burden, the results cannot be generalized because the sample was non-random and the design is cross-sectional. Longitudinal studies are required to observe the effects of client behaviors over time.

### Collective Critique of Caregiver Burden Studies.

A number of strengths and inadequacies can be identified in the research literature on caregiver burden in mental illness. The vast majority of the studies reviewed were done with relatively small numbers of subjects, who volunteered to participate in these studies thus making them subject to problems of selection bias, as noted earlier. The study samples were composed mainly of white middle class members and thus excluded families of other socio-economic classes such as the low income groups. Although the findings of these studies cannot be generalized to the general population, it is important to note that they tend to agree on the fact that family members of relatives with mental illness do experience similar kinds of burden; thus demonstrating convergent validity as a group. These studies have consistently yielded similar findings about the nature of burden to largely Caucasian subjects in the US for example, the impact of the mental illness or disability on caregiver health.

A more fundamental problem concerns the difficulty in the operationalization of the concept of burden. Gubman et al., (1987) noted that many authors operationalized this concept differently. For example, burden may be conceptualized as dangerous behavior of the mentally ill client and it encompasses intent, fear, action, and arrest. For others, it may be seen as the time commitment, cost and the emotions and feelings about the caregiving situation. Therefore, caregiver burden is a complex and multifaceted concept. Although most studies view burden or stress as negative, Gubman et al., (1987) argue that stress in some cases can enhance growth . Therefore, the family might be strengthened and become a more cohesive group in understanding mental illness. Another consideration is that families are under stresses of life all the time. However, it is not known which stress is more detrimental to the family well being. To answer this question, families need to be studied under both conditions; that is, under the stress of adjusting to a mentally ill member and under other stresses of family life.

Although some studies have attempted to explore more complex interrelationships between variables, small sample sizes have often meant lack of statistical power. Some studies as pointed out earlier have used correlations to demonstrate these interrelationships. Correlations are known to be unstable and are adversely affected by small sample sizes (Glantz & Slinker, 1991). However, it is interesting to note the consistency of results from small and non-random samples, particularly consistency of negative correlations between health and subjective and objective burden. This suggests that burden does have a detrimental impact on the health of the caregivers, and that health measures may be appropriate indicators of burden in outcome studies.

One point worth mentioning is the mix of the studies that were reviewed which included both quantitative and qualitative methodologies. The qualitative studies generated very rich descriptions and the felt experiences of the families. These descriptions are important for enabling the health workers to target the specific needs of the caregivers. It was quite impressive to find these studies because in places like Botswana where research is still at its infancy, this work can be very valuable in guiding as an exemplar.

Despite the value of quantitative research, there are some important aspects of the phenomenon of caregiver burden that quantitative methodologies are ill-equipped to illumine. An important example is an understanding of subjective experiences of living with a mentally ill person in the context of Botswana. Some of the instruments utilized in the studies reviewed have relatively high internal consistencies as evidenced by their alpha levels (Thompson & Doll, 1982; Robinson, 1989; Mintzer et al., 1988; Reinhard, 1994). While reliability testing using Cronbach's alpha is a useful way to test internal consistency of a scale, high correlations of over .94 are often caused by redundancy between items. Although high intercorrelations may suggest unidimensional measures, burden is not a unidimensional concept.

## Caregiver Support

Following deinstitutionalization, the focus of research was to find ways that could maximize support to reintegrate and sustain the mentally ill in the community. However, it was later realized that in order to achieve this, their immediate and natural support networks also needed strengthening. Hence there was a shift in the research focus to target the caregivers and find means of optimizing their support which would in turn sustain the integration of the mentally ill in their communities. This part therefore, reviews research on social support to the family caregivers for the chronically mentally ill.

The burden on the family to provide care to the mentally ill is well documented in the literature (Doll, 1976; Hatfiled, 1987; Thompson & Doll, 1982). Doll and Thompson (1982) raised the question "who provides the support for the support systems?" ( p. 379). This question is valid and very significant because the successful integration of the mentally ill depends to a large extent on the support the mentally ill receive from their families. A comprehensive review of survey studies on discharged patients found that 65% of the patients in the U.S. returned to their families (Goldman, 1982). However, these patients do not necessarily live with their families. They stay in hotels which serve as half way houses or boarding homes. Goldman used these figures to demonstrate the potential for family burden. His contention was that whatever treatment was to be offered to the chronically mentally ill should include consideration of the family as a potential source of support. In Botswana, 100% of the discharged patients return to their families (Ministry of Health Annual Report, 1984). Therefore, understanding families' support and ways to mobilize the support base is very critical for better mental health outcomes in this population.

In an exploratory study, the effects of stress and social support and their interaction with psychological well-being among 87 family caregivers of impaired elderly were examined (Baillie, Norbeck, Barnes, 1988). Perceived stress of caregiving was measured by a 16 item questionnaire developed for this study (internal consistency reliability .90) and each item was rated on a 5-point Likert scale ranging from no stress to high stress. Satisfaction with social support was measured with an 8 item questionnaire also developed for this study with a standardized alpha of .84. The psychological distress was measured with the Mood States (POMS) which is a 65 item adjective rating scale with a test re-test reliability ranging from .65 - .74. The sample of caregivers was predominantly female, married, and white. The stress-buffering social support model was utilized to test both the main and interactive effects of perceived caregiver stress and social support. The secondary purpose was to explore demographic variables and characteristics of caregiver situation that might contribute to additional explained in psychological distress in caregivers.

The results indicated that the caregivers of the impaired elderly who had been providing care for an extended period of time and had low social support were at higher risk for psychological distress or depression. Social support was also strongly related to the psychological well being in this sample as a main effect. However, the extended period of care was not defined. Thus, it is unclear at what point family caregivers begin to experience distress and depression. The study did not describe what social support factors actually contribute to satisfaction. However, the study indicated the caregivers who are caring for a mentally ill impaired elder for a long time, and who have low social support are at high risk for psychological distress or depression. Although the standardized alpha for internal consistency reliabilities for this sample were high; further research is needed to explore factors that contribute to satisfaction and to understand how support facilitates coping with the demands of the mentally ill.

Eighty-six family caregivers participated in a small group to discuss their experiences of burden in caring for their mentally ill relatives (Francell, Conn, & Gray 1988). The sample was drawn from eight consortium area of mental health and participants responded to adverts placed in the local newspaper. Focus groups of 10 to 15 family caregivers (N = 8) responded to open-ended questions during a session. Interviews were tape recorded and later on transcribed and this assured the possibility of validation and confirmability of the data. Data were analyzed using the constant comparative method. Data were sorted into categories based on similarities and differences. The analysis of focus group transcripts revealed a spectrum of concerns. The family caregivers attested to the painfulness of burden. The area of concern included crisis situations where the family caregivers found themselves totally responsible for their relatives. The families felt deserted by the mental health providers at crucial times when needed the most help. The findings indicated the lack of formal support to the family caregivers from mental health providers.. The participants also alluded to inadequate community resources such as lack of information about mental illness.

While focus groups offer the researcher the advantage of tapping reality from the participants' points of view (Krueger, 1988), the method has inherent problems. The ability for the researcher to assemble the group and to conduct the session effectively can be difficult (Basch, 1987; Morgan, 1988). The findings may also be biased by the dominant or highly opinionated members of the group (Stewart & Shamdasani, 1990). The way the sample was selected limits the generalizability of the findings and the responses of the group members may not be independent of one another (Stewart & Shamdasani, 1990).

The problems elicited in this study underscore the fundamental importance of support for the families if community care is to be successful and beneficial to all involved. The community mental health program was developed with the notion that the patients and their families would be given support. Health professionals may also need to know what modalities to employ to provide the needed support to families. More research is needed in order to understand the situation of the family caregivers, to develop strategies that can best ameliorate their problems, and to find better ways for mental health professionals to maximize the provision of support to the families.

A descriptive pilot investigation of 20 family caregivers to psychiatric clients was reported (Chafetz & Barnes, 1989). Subjects were recruited through community organizations and clinical services. Semi-structured interviews were conducted and tape recorded. The participants were asked to state three important problems that they experienced in caring for their relatives. An inventory of problems caregivers experienced and their sources of assistance was provided. Data were analyzed qualitatively, however, it is not clear which qualitative method of analysis was actually employed.

The findings indicated that the family caregivers experience a broad array of problems ranging from emotional, fears for the future, managing medications, problems getting or using professional help, lack of respite care, financial pressures, and housing problems. It is obvious from this study that caregivers of the mentally ill have many problems despite the availability of mental health services. The findings further underscore a discrepancy between the available support services and the actual utilization of these services. The family caregivers were uncertain and dissatisfied about the support they received. This study heightens the need for further understanding of support from the caregivers' perspectives as well as the interactive and working relationships between the families of the mentally ill and the mental health professionals.

Skodol-Wilson (1989) explored and described the process of family caregiving for the elderly with Alzheimer's disease (N = 20) as experienced from the perspective of the caregiver using the constant comparative method. The results indicated that extended home care support services and survival strategies for the family caregivers are neglected but sorely needed. The results also illuminated how the family caregivers tried to cope with the problem through three stages of "taking it on, going through it, and turning it over." Each stage has characteristic properties, problems, and coping strategies and the whole process is a consciously examined and self-reflected difficult means of surviving on a day to day basis. It is clear from this study that family caregivers carry a lot of responsibility in taking care of their relatives and present diverse and unique problems depending on the situation facing them. The major problem facing nursing is how best to enable families to cope with this situation and to devise modalities that can maximize and strengthen the provision of support to the family caregivers. Further research is needed to explicate this area to understand the situation of the caregivers so that appropriate intervention can be developed.

Norbeck, Chafetz, Skodol-Wilson, & Weiss (1991) investigated the social support needs of 60 family caregivers of child, adult, and elderly psychiatric patient to determine their unique and common support needs. Structured interviews were conducted using open-ended questions and probes. Content analysis interview data were utilized to identify support categories and their properties. Differences in support needs found across the three age groups reflected the stage of development of the person being cared for and the stage of development of the family. The caregivers of the children and adults adjusted and reorganized their lives around the caregiving demands of their relative. In contrast, the caregivers of an elderly relative were caught up in the crisis of adapting to the sudden, intense caregiving needs. The findings from the caregivers of adult psychiatric patients showed a consistent pattern reflecting extreme lack of support. Therefore, ways of how to provide support to family caregivers of adult psychiatric and elderly patients need to be identified. The study sample was small and mainly white middle class. There is need to extend this study to ethnic, cultural and socio-economic groups. Further research should also aim at identifying general common and specific support for caregivers of different populations.

In this descriptive qualitative study, Mogorosi (1994) explored the needs of families caring for a dependent adult family member with a chronic illness. A convenience sample of ten (N = 10) family members were interviewed using a 17 item structured interview guide. Snowballing techniques were used to access the potential informants. The age of the caregivers ranged from 25 - 68 years. The duration of care ranged between 1-168 months and mostly daughters, wives, mothers to the dependents were the ones that provided the care. The dependents' conditions included epilepsy, hemiplegia, HIV/AIDS, and old age. Themes that emerged included physical skills for example, feeding, bathing, dressing, walking, managing treatment, turning position, social skills, psychological support, and need for information.

Findings indicated that all caregivers were female relatives to the ill persons. Family caregivers identified social needs, need for information about the condition and care of patients with such conditions, and help with finances as their greatest needs. The lack of finance proved to be a source of problem for caring as almost all the caregivers were unemployed and thus depended on their other family members to provide for them. More than half of the sample (60%) turned to traditional doctors and spiritual healers for information and consultation. No nurses visited the homes to provide care for either the patient or inform the caregivers about what and how to provide care for their ill relatives. More assistance was needed by the caregivers who provide care to their dependent relatives in the home to give them information they needed. More research is needed to learn more about the needs of families caring for their dependent ill relative in the home in order to develop well structured home-based programs for long term care.

Although this study revealed the problems that the caregiver in this sample faced, the results cannot be applied to the general population of caregivers. The study also uncovered the problems of home based care.

Mantswe (1994) conducted a study to assess aftercare services for persons with long term mental illness living in the community. The main aim of this survey was to identify the needs of people with long term mental illness who live in the community in Gaborone and to assess whether the services are delivered in a manner that is responsive to their needs. A sample of forty three (N = 43) consisting of fifteen (n= 15) patients, eleven (n= 11) family members, seventeen (n=17) health providers was systematically selected by random. Although the family members were included in this sample they were mainly to answer questions for patients who could not answer questions well. The mentally ill interviewed were all unemployed, had low level of education, and mostly lived with their relatives.

The results of the study showed that the needs of patients were not met by the services currently provided. The kind of treatment patients got from service providers was mainly medications and other rehabilitation and support needs were neglected. If support existed it was primarily informal. This study also indicated a strong link between mental illness and low socio-economic status, illiteracy, unemployment and alcohol consumption. This pointed out to the burden shouldered by the families of the mentally ill. This underscored the importance a specific study that would elicit information about the situations of the families of the mentally ill in the community.

In an exploratory design, Kgosidintsi (1990) selected a convenience sample of twenty five careers (n= 25) and eleven nurses (n= 11) to assess the day to day care and welfare of schizophrenic clients living in the community. The sample was drawn from urban, semi-urban, rural and semi-rural areas where there was community mental health nurse. Both qualitative and quantitative data were collected using semi-structured interviews, unstructured observations and documentary searches. The findings indicated the role of community mental health nurse is influenced by the availability of resources such as transport, which emerged as a major problem. Three main activities emerged as the main roles: assessing the clients' mental health status, prescribing treatment, and administration of treatment through injection and other routes. Carers complained of inadequate care and support, social and economic burdens of caring for clients in the community, and expressed the need for periodic admission to hospital and rehabilitation services for discharged clients. The study concluded that the role of the community mental health nurse as curative. Although this study identified some of the problems the families face in the care of their mentally ill relatives in the community, a need to specifically understand the situations of the families from their perspectives was imperative. It was also necessary to understand what ways families employed to live with these situations. This understanding can be used by health providers as a springboard to develop interventions that are relevant and appropriate for the needs of the families.

Pretorius (1994) conducted a study on the network orientation and social support as a moderation of stress-depression relationship in South Africa. The study focused on the interaction of network orientation, which refers to the individual's willingness to use his/her available social support resources and social support in moderating the stress-depression relationship. The study was conducted amongst students of historically black university in South Africa - the University of Western Cape (N = 450). Two measures of social support, the social support questionnaire (SSQ: Saranson, Levine, Bashman & Saranson, 1983) and the Perceived Social Support Scale (PSS; Procidiano & Heller, 1983) were used.

The results indicated that network orientation independently as well as in interaction with social support, can moderate the effects of stress on depression for all subjects. An analysis of the interaction however, indicated completely a different interaction process for the two groups. For people with a positive network orientation, the buffering hypothesis was supported. For people with a negative network orientation, the results indicated that individuals who benefit the most from stress reducing functions of social support are those with average rather than high or low support. This study is significant because the author used instruments developed in a different culture to collect the data on people of another culture. This somehow adds to the psychometric strengths of the instruments and their cross cultural applicability. The results seem to be consistent with previous findings on social support as a moderator of stress.

## Summary Review of the Studies on Caregiver Support

Generally, support for the caregivers of the mentally ill has not been extensively researched. More vigorous and robust investigations are needed to in order to find ways that family caregivers can be provided with support to enable them to cope with the caregiving situation. The results from the studies have identified some discrepancies between the responsibility of caregiving and the support needs of the families. These were small, mainly white and convenience samples. The samples were also limited to the users of the social and health services, leaving out those who do not utilize these services. As Tessler, Killian, & Gubman (1987) noted that the most isolated and stigmatized family members may be hardest to include in research samples. Thus, the findings must also be interpreted with caution.

Generalizability of these findings cannot be assumed. It is important to extend the studies to other cultural groups in order to identify similarities and differences in the conceptualization of support among different ethnic and socio-cultural groups. Procidano and Heller (1983) maintain that perceived support and support provided by networks are not identical. The findings of these studies however, provide initial foundation for better understanding the support needs of family caregivers. The majority of them utilized qualitative methods which supply rich data in this area. Nevertheless, there is still need for further study focusing specifically on the needs of the families within particular socio-cultural and political contexts. Although, the research focused on family caregivers, the unit of analysis was basically individuals and not dyads, groups, or families.

## Support for the Patient

This section reviews literature that examined social support for individuals suffering from mental illness. Research on support to the mentally ill focused on two main ideas. First, that social support is viewed as either having some direct protective influence on the person (Cassel, 1974) or as buffering effects of the stressful life events (Cobb, 1976; Dean & Lin, 1972; Norbeck, 1985; Tolsdorf, 1976). The focus of research on the social support to the patient concentrated on the assessment of networks. Social networks refer to the social connections provided by the environment and can be assessed in terms of structural and functional dimensions (Marsella & Snyder, 1981). Structural network is characterized by size, density, multiplexity, etc., while network functions include the provision of information, comfort, emotional support, material aid, etc., (Procidano & Heller, 1983). If networks provide support, information, and feedback (Caplan, 1974) then perceived support is the extent to which an individual believes that her/his needs for support, information, and feedback are fulfilled (Procidano & Heller, 1983).

The definitions and conceptualizations of social support in nursing and general literature continue to conflict and are inconsistent. Social support is sometimes seen from the perspective of the of the individual receiving it. The patients' perception of support were investigated by Gardener & Wheels (1987). The goal of the study was to ascertain if the patient's perspectives of social support varied among the medical, surgical, and psychiatric hospitalized. The findings were a part of the larger study examining patients' and nurses' perception of support obtained through a convenience sample (N = 128) . The sample was drawn from a teaching acute-care hospital using medical, surgical, and psychiatric units. A structured interview and a questionnaire were used to collect the data. The questionnaire used was the Supportive Nursing Behavior Checklist (SNBC) which had 67 items. The patients were asked to rate on a 7-point scale the relative importance they assigned to each of the 67 items. This was the first time the SNBC was used. The respondents who were psychiatric patients constituted 23%. The analysis of covariance was performed for each supportive items with age, specialty areas, and other demographic variables. The results indicated a significant difference among the three groups of patients in their perception of support needs ($p < .05$). The psychiatric patients perceived the provision of moral support to be more relatively important than did medical and surgical patients. However, the results should be considered tentative because this study was preliminary with a small and a non-randomized sample. Although the patients across the three specialty areas appear to have more agreement than disagreement on their perception of support which ranged from physical, individualized care such as involving the patient, assistance in controlling behavior, moral support and confidence; their differences yield interesting information. Surgical patients gave more importance to feeling confident and to physical measures, psychiatric patients ascribed more importance to nurses helping them to solve problems, and medical patients ascribed more importance to the friendliness of the nurses. The results inform us that perceived support is when an individual's needs are recognized so they depend on the situation.

An understanding of the range of potential and actual social network contacts for serious mental illness is important for targeting appropriate interventions to enhance their community supports. In a study of (N = 125) clients who were 91% Caucasian and 9% African-American Walsh (1994) surveyed clients of two urban community treatment teams to determine their overall social network size, personal or support network size. The full-support model of case management which deals with the teaching of coping skills with clinical management and provision of support to clients was done. The philosophy underlying the model is that persons with serious mental illness reach maximum functional capacity when supported in their natural environment. This is an example of action research in which the case managers worked with 15 -18 clients and assisted them with basic survival needs such as housing, income, and health. Case managers conducted client groups each day. Four components of support were utilized as dependent variables: social network size, social network clusters, personal network size, and personal network clusters.

The results indicated a mean social network for this sample was 14.4 with a standard deviation of 8.2 and the mean number of cluster involvements was 4.9 and standard deviation of 1.9, slightly higher for this sample than those reported in related studies of the mentally ill (Atikinson, 1986; Cutler et al., 1987; Greenblat et al. 1982). These other studies found network sizes of 10-13 people in their samples. The mean personal network size of 8.9 with a standard deviation of 7.4 was found. This finding on personal network was interesting because these were persons identified by respondents as actual supports. These results were considered substantial given the frequent findings in other research that persons serious mental illness do not easily connect with others (Beels, 1981) and are lonely (Sullivan & Poertner, 1989). Walsh contends that family members make up a large segment of the personal network (40%). Although family members are important contacts, they are not necessarily conducive to community integration.

Although these study results show potential for maximizing support for the mentally ill in the community, the study does not indicate how the network systems impacted on the health outcomes of these patients. For example, did those with a large social or personal network have better health outcomes than those who did not? This study was composed of a large number of Caucasian (n=113, 90.4%). The under representation of other groups limits the generalizabilty of the findings to other ethnic groups. Studies of this nature need to be expanded to include other groups of people (non-Caucasian) to determine their social and personal network patterns and influences.

The belief that one's physical health and psychological well being depend to a great extent on one's nurturing relationship is a folk wisdom. Hubbard, Muhlenkamp, & Brown (1984) investigated the relationship between the individual's perceived level of social support and performance of specific, positive health practices (nutrition, exercise, relaxation safety, and substance abuse). Two hypotheses were tested. First, that a positive association would be found between the social support and health practice variables. Second, that married participants would score significantly higher on the both social support and health instruments than their married counterparts. The sample consisted of 97 volunteers with a mean age of 70 and 97% were Caucasian and 88% of the individuals from a senior citizen center were approached to participate (57 female and 40 male).

The Weinert Personal Resources Questionnaire (PRQ II,) consisting of 25 statements that were responded to on a 7-point Likert scale and tapped on five dimensions of social support by Weiss (1974) was used (Weinert, 1981). According to Brandt and Weinert (1981) the instrument has a demonstrated Cronbach's alpha of .89. The positive health practices were measured by the Life Style Questionnaire (Brown, Muhlenkamp, & Osborn, 1983). This instrument has 24 items and its validity was established by Brown et al., (1983) who used it together with Stevens' Point Health Assessment (1980) and items for this scale are not given. A high correlation of .83 was found between the two instruments. The test-retest reliability was .88 and Cronbach's alpha was .76 on a sample of 383. The instruments used to collect the data had a very high internal consistency.

The results indicated a highly significant correlation of .57 (p< .0001) between social support and health practices. A stepwise multiple regression analysis showed that social support was the most significant indicator and accounted for 34% of the variance in the positive health practices. The results indicated that people with adequate social support would lead healthier lifestyles. Although the link may not be causal in nature but the relationship between the two is important. The second hypothesis was not supported. The results have demonstrated important relationships between social support and health practices. However, these results should be interpreted cautiously because the sample was a convenience one and was predominantly

Caucasian. The sample was also selected from a citizen center and thus excluded other people who did not utilize this center. Therefore, generalizability of these findings cannot be assumed.

Bennette (1988) explored the relations among stress, social support, and self-esteem in a non- random sample (N = 45). This study aimed at conceptualizing social support as a moderator of stress. The main hypothesis to be tested was that social support is positively related to self-esteem and stress is negatively related to self-esteem. The buffering hypothesis which proposes that social support acts as a buffer of stressful life events, without strong direct effects on self-esteem independent of stress, was also tested for this sample. A descriptive, correlational cross-sectional study was done. The sample was composed of Caucasians (N = 42) and Hispanics (N = 3). Stressful life events were measured by a 55 item Recent Life Changes Questionnaire (RLCQ) (Rahe, 1975). Social support was measured by the Norbeck Social Support Questionnaire (NSSQ) based on Kahn's (1979) conceptual definition of social support which measures the individual's perceived availability of interpersonal resources and degree of integration in a social network. The test-retest reliability findings for the NSSQ range from .85 to .92 for functional subscales in this study. Self-esteem was measured by the Tennesse Self-concept scale with a test-retest reliability of .92 in this study and consists of 100 self descriptive statements.

Results showed a relationship between social support and self-esteem. Simple correlations between self-esteem and categories of social support were significant at .05 level. The buffering hypothesis was tested by a stepwise multiple regression analysis of self- esteem on social support, stress and the social support and stress interaction term. The buffering hypothesis was supported but the significant main effects including the independent effects of social support and stress did quite well in accounting for 30% of the variance ($r = .62, p = .01$).

The buffering model of stress, social support, and well-being was not supported in this study. Rather a direct overall positive relationship between social support and self-esteem was demonstrated. Failure to find support for the buffering hypothesis may be due to very weak, inconsistent effect of stress on self-esteem in the sample. The stronger correlation between social support and self-esteem for the high stress group than the low stress group suggests the concepts of buffering is still worth pursuing.

It is generally agreed that social support networks of people with mental illness are deficient or impoverished (Pattison & Pattison, 1981; Cohen & Sokolovsky, 1978; Lipton, 1981). The degree of impoverishment may be related to the severity of or duration of mental illness. Crotty and Kuyls (1985) investigated the social support network of schizophrenics and their significant others. The Social Support Network Inventory (SSNI) with a standardized alpha of .82 depicting a high degree of internal consistency was used to collect the data. The sample was composed of patients ($N = 56$) and their significant other ($N= 56$). The sample was almost all white (96%) and was drawn from an outpatient community mental health facility in Chicago. This sustaining program serves persons who are severely and chronically mentally disabled and require commitment from the service provider for frequent and extended periods. The clients perceived their network to be higher consisting of eleven or more members than those perceived by their significant others. For the clients, the mean size of the network was 6.4 and for significant others, the mean size was 5.3. The Pearson correlation coefficients indicated significant differences ($p < .05$) between the clients' and significant others' perceptions of network size. Nevertheless, the clients and significant others agree that the network is small, supporting the findings existent in the literature (Pattison & Pattison, 1981; Cohen & Sokolovsky, 1978, Lipton, 1981). However, significant others may not report all the network members that the clients have. The agreement and disagreements rates between client respondents and their significant others regarding the strength of the clients' social support were obtained and compared.

The study elicits important findings that the patients' perceptions of their own networks are different from those of their relatives. Although the significant others attest to small client networks, they feel that patients have a great deal of support, while the patients themselves experience little support. Tilden and Gaylen (1987) contend that big network systems do not necessarily guarantee quality support. Although the study utilized instruments with high reliability and validity, the results are nonetheless not generalizable because the sample was exclusively white, it was non-randomized, and obtained from an ongoing program of assisting the clients build and maintain the network systems and this excludes the mentally ill who may not utilize these facilities. There is need to include other groups that may not utilize these programs and other cultural groups to see how they conceptualize their support systems. The findings however, demonstrate the importance of a system of management in assisting the severely mentally ill in maintaining and sustaining networks.

Several important patterns are found among the networks of schizophrenic patients (Beels, 1981; Sullivan & Poertner, 1989). The networks tend to be smaller than those of normal, networks tend to be highly interconnected around kin with only a few diffuse nonkin contacts, relationships with kin tend to be dependent whereas those of nonkin are more reciprocal, and smaller networks may predispose some patients to rehospitalization (Beels et al., 1984; Bernstein, 1983; Cutler & Tatum, 1983; Henderson, 1980). In their attempt to investigate the aforementioned patterns, Cohen and Kochanowicz (1989), examined the social network dimensions for a broad range of inner-city black schizophrenics. The results confirmed the these patterns described previously for other schizophrenic populations. The findings reinforce Webtermeyer and Pattison's (1989) contention that these network patterns are found across schizophrenic populations. Although the sample was randomly selected, the psychometric properties of the tool and the theory utilized in the study were not reported. The authors also did not report how the random selection of the sample was obtained.

Using a convenience sample of mentally ill patients (N = 213), Sullivan and Poertner (1989) examined the social support and social networks and their relationship to three outcomes using a five scale questionnaire (four scales coefficient alpha > .70 and one scale coefficient alpha > .32). The sample was comprised of consumers of community support services in a large western state. Pearson correlation matrix was used to demonstrate relationships between conceptualization of social support and the experience of stress, frustrations and use of leisure time.

The results indicated fewer intimate contacts, attesting that the mentally ill have smaller networks than normal individual, and that the family contacts were dominant among this group. Also, no meaningful relationships between network variables and clients' perceptions of difficulties or troubles in their lives were found. The authors contend that this casts doubt on the buffering effect of social networks. While the scales address the question of the expansion or shrinkage of the client's social network as well as perceived importance, longitudinal and more in-depth qualitative studies are needed to understand the perceptions of the mentally ill regarding their social networks.

In doubt of what the community support system actually meant for the chronic mentally ill patients, Cutler, Tatum, and Shore (1987), examined three different sorts of community support programs (medication, case management, and socialization groups) and compared a sample of patients within them with respect to network size, role performance , and demographic variables. Utilizing the Pattison's psychological Kinship System Inventory to capture information on social networks, a convenience and an exclusively white sample (N = 30) was from the three programs and studied. In addition, structured interviews, which lasted from 40 minutes to 2 hours were conducted together with a 90 item symptom checklist. One way analysis of variance was used to test the difference between the three groups.

The network profile showed a significant variation among the three treatment groups in terms of size, density, and frequency of contact. The socialization group had a larger network size than the other two groups (16.5, SD 5.4), case management (9.7, SD 4.5), and medication group (7.3, SD 4.0). Despite the large network for the socialization group, little went on between patients and their network in terms of reciprocity (SD 1.4 as compared with the other two groups SD .8 & 1.0), frequency of contact (SD .9, .6 &.6) and contact. The case management group had significantly fewer hospitalizations and more frequent contact with their network members than the two other groups. Although it is important to note that case management influences health outcomes, the study does not provide answers to the best way to build networks, which variables should be enhanced, or whether or not building networks actually results in effective reintegration into the community life as opposed to simply what Talbot (1979) described as "transinstitutionalization."

The results however, suggest that those patients who eventually form better developed networks may be more likely to adjust to and be better satisfied with their life. More research needs to focus on the long term efforts of intensive programs to elicit what helps and how long it takes for functional network development to occur.

Utilizing Weiss's (1974) conceptualization of support, Baker, Jodrey, Intagliata, and Straus (1993) followed chronic mental patients receiving community support services (CSS) for a period of nine months. The adequacy of social support from family, friends, and others was measured by the Global Assessment Scale (GAS) which has an interrater correlation of .64 was used to predict change in client functioning. Data was obtained from a stratified random sample (N = 844, 86% white) served by seven CSS programs; although it is not reported how the random sampling was achieved.

The multiple regression model accounted for 48.9% of the variance ($R^2 = .489$, $p < .01$). This finding of a significant contribution of social support to predicting change in the global functioning agrees with the growing body of research emphasizing the importance of social support for maintenance of chronic mental patients in the community. Although the sample was randomly selected, the white exclusiveness of this sample limits its generalizability to non white populations.

In a quasi-experimental study, Goering, Wasylenki, Farkas, Lancee, & Ballantyne (1988) used a survey instrument at four time periods to compare eighty-two patients' occupational functioning in a rehabilitation-oriented case management program with another eighty-two patients in a control group from the same setting before the case management program was established. Chi square analyses were used to test for differences between the program and the control group at $p < .05$.

The patients were categorized as having low, moderate or high functioning based on the amount of time they had been able to function in any instrumental role in the previous 6 months. Patients in the program had higher occupational functioning (37%) than did the control group (32%). Surprisingly, patients in the control group were more independent than those in the program. Thus attesting that programs can foster some dependency on the patients. The high level of functioning of the patients on the program on the other hand, demonstrates the potency of the relationship between the case manager and the patient. Although the two groups differed significantly in their occupational, the patients did not differ in their recidivism rates. The study results suggest that rehabilitation-oriented case management can influence patients' outcomes toward improved occupational functioning. Further investigation on causal relationships need to be done because low case loads are indicative of how more concentration and attention can be important in attending somebody's to problems thus indicating that the more support one gets the better their problems will be dealt with.

Goering, Durbin, Forster, Hons, Babiak, and Lancee (1992) described the social support networks of supportive housing resident and compared their network size and composition, adequacy of support received, and the amount of support received with those of the other psychiatrically disabled populations using the Inventory of Socially Supportive Behaviors (ISSB) (Barrera, 1981). This instrument has an established test re-test reliability of measures of network size (r = .88) and support satisfaction (r = .69). The results indicated a network size of 11.5 and respondents reported less family, friends , more providers and housemates in their personal support network. Residents who reported greater need for physical aid support reported less satisfaction with physical aid (r .- 41 p < .01) and less satisfaction with overall support (r = .- 29 p < .05). Therefore, residents who had more people in their network and who received more help from their network also had higher perceived needs for social support. It is plausible to say that enriched social environments of supportive housing create higher levels of satisfaction than does living in unsupervised or family settings.

The authors compared their findings with those other networks studies and found that the network composition differs with those reported in other studies; that is to say, fewer friends and family members and more professionals were named. The higher proportion of professional health care providers raises a concern because the greater numbers of staff in the network suggests dependency. However, the study provides a promising trend that if mental health providers can work with the families and teach them supervision skills, they can be able to make an impact in their relatives' lives. This possibility needs to be explicated and studied. This kind of study will tremendously benefit those settings where there is a shortage of mental health professionals and no alternative housing for the mentally ill such as in Botswana.

Measures of social support are frequently limited to counts of contacts with friends, relatives, or other. In their quasi-experimental study, Meels and Murrell (1994) compared social networks of 27 severely mentally ill clients of two community mental health centers with those of 19 clients who had less severe disorders who were receiving individual therapy through an outpatient adult services. Network analysis was performed with the Network Analysis Profile (NAP) which has an interrater reliability of .83 to .92 (Sokolovsky & Cohen, 1981). This measure looks at the counts of contacts with friends, relatives, or other people who do things with them, who are supportive, or for whom they do things.

The results indicated significant differences between the severe mentally ill and the comparison group on these network characteristics in terms of size and configuration with means of 6.00, SD 3.48 and 8.21, SD 2.32 for the less severely mentally ill group.. The social networks of the severely mentally ill were smaller and less reciprocal than those of other clients, a finding that is consistent with previous research. The study supports the notion that the network of severe mentally ill was of more quality than of the comparative group indicating the quality of services and guidance that this group received from the providers. This study has yielded important results indicating that the mentally ill who are under supervision tend to have better quality social support from their network. The authors do not indicate the length of the period these mentally ill had been receiving services from this community mental health centers. No criteria are mentioned for selecting these clients into these programs. The clients need to be followed over a period of time to assess their adjustment and also to determine the effectiveness of the contacts intervention.

Godley, Sain, McClure, Smerken, and Manion (1988) determined what components of psychosocial rehabilitation made a difference by randomly assigning 24 schizophrenic patients who had been hospitalized at least two times or who had a total 300 days hospitalization during three years to the community support aide intervention or to a control group that received usual community mental center programs. The study encompassed a period of one year using a pre-post test control group design to assess the effect of the intervention. Chi square was used to analyze the differences.

The results did not indicate any significant difference between the two groups on exacerbation of symptoms, hospital days, and total hospital admissions no were there differences in terms of consumer satisfaction. A significant difference was noted only in the areas of physical activity (4.80 p <.05). The sample of the study was too small and that might have resulted in low statistical power to detect the differences. This makes it difficult to say unequivocally that a particular intervention may or may not reduce hospitalizations. The strength of this study is that it has provided a model for evaluating psychological rehabilitation programs. While this was a randomized experimental study, its generalizability is limited because the sample was very small and predominantly white.

In this position paper, Uys (1992) points out that currently the psychiatric services in South Africa are curative and hospital based. This leads to services being expensive and stigmatizing to the patients with mental illness. She advances a notion that primary health care workers are not involved and primary prevention is neglected. The paper argues for the differentiation of psychiatric services to be organized at primary health care level in which primary prevention and early diagnosis should constitute 70-80%. Secondary level which is mainly institutional, 10-20%, and tertiary level which will aim for more chronically affected patients at 10%. At primary health care level, care will be provided in the community, mostly by the families and communities playing a central role in mental health. The paper concludes by making very strong recommendations for shifting the care of the mentally ill from institutional to community based care in South Africa. The recommendation have very serious implications and challenges for the families in providing care for their relatives.

## Summary Review of the Studies on Support to the Patient

A number of strengths and inadequacies can be identified in the literature pertaining to the social support for the mentally ill in the community. The vast majority of the studies were done in settings where the severely and chronically mentally ill were already in programs that assisted them with integration into the community. This renders these studies subject to selection bias thus affecting their internal validity. The studies focused on network composition and size. Only two looked at the quality of support the patients experienced from their networks. The quality of support that networks provide are important particularly because the size of the network does not necessarily guarantee quality of support.

Social support is a multidimensional construct (Norbeck & Tilden, 1988; Durcharme et al., 1994) and it is dynamic depending on the context and patient's characteristics. Therefore, longitudinal studies will be ideal to elicit data that can reflect change over time. Most of the studies reviewed did not report the theories that they utilized. However, two tested the buffering effect of social support and found conflicting results. Nevertheless, the buffering effects of social support has been well documented in the literature, but just how buffering may work is still not understood (Cobb, 1976; Cohen, 1988; Dean & Lin, 1977; Norbeck, 1985). Also, further testing of the buffering hypothesis with other non western populations is worth considering in order to identify whether similar findings will be obtained.

The samples selected for the studies tended to be relatively small, non-random, and predominantly white. Only two studies had randomly selected samples. However, their samples were too small to reach statistical power as suggested by Nunnally (1978) that at least five times as many subjects as items be recruited in order to reach desired statistical power. These are major limitations to the generalizability of the results to non-white populations and other cultures. Research findings from western culture cannot simply be transferred to other cultures without retesting (Norbeck and Tilden, 1988). In this post-modern era, Anglophone normative performances should no longer constitute a gold standard for other cultures.

Another problem pertains to the different conceptualizations of social support and that consensus about the definitions has not yet been reached. This is indicative of the need for more qualitative research in this area. Most studies did not report the theories that were used. This may be accounted for by the different conceptualizations and that a theoretical basis for the study of social support in nursing is not yet formulated. More theoretically based research is needed in this area. The studies that used a theory to study social support in nursing borrowed it from the psychosocial disciplines. This is problematic because nursing is practice discipline and it has to develop theory that can guide nursing practice. There is great need to clarify the conceptualization of social support through qualitative research before the testing of hypotheses. The different conceptualization of social support also makes its measurement problematic because this has led to the utilization of different measures and it is not clear whether researchers are measuring a different or the same construct.

Another point worth noting is that of the studies reviewed, none utilized qualitative methodologies. Despite the value of quantitative research, there are important aspects of this phenomenon that quantitative methodologies may fail to illumine for example, the conceptualization of social support warrants qualitative research. This will provide a better understanding of social support.

Although sample selection was a major set back of the majority of studies, the instruments utilized in some of these studies had high internal consistencies indicating high reliability. A few instruments have reported psychometric properties such as the Norbeck Social Support Questionnaire and specified direction of support, content, source of social support, duration, and the level or interaction of the dimensions. Although there are numerous limitations of these studies, they have nonetheless generated invaluable literature that provides a sensitization about the complexity of the construct social support.

## Intervention Studies

Concomitant with research on caregiver burden, some work began to focus on intervention strategies that could ameliorate the situation the caregivers were in. This section reviews empirical evidence concerning the effectiveness of interventions that were designed to help caregivers to cope with their caregiving situation, improve the ability of caregiver to meet patient needs, to prevent or reduce caregiver burden, and to prevent or reduce the deleterious effects of stress on health and mental health status of caregivers (Biegel et al., 1991). The review of the literature will be guided by six central questions: 1) What are the nature and characteristics of interventions for caregivers; 2) How widely have particular intervention modalities been utilized with caregivers of the mentally ill; 3) Are these caregiver interventions effective in preventing or reducing caregiver distress; 4) Are there differences in the effectiveness of caregiver intervention or what seems to work better; 5) What are the strengths and weaknesses of these caregiver interventions; 6) What is the feasibility, utility, and applicability of these intervention modalities in other cultural settings such in the case of Botswana.

Intervention research has been organized into three main categories namely: support group intervention, psychoeducation interventions, and clinical or direct service interventions (Biegel et al., 1991; Hatfield, 1987). Support group interventions are designed to provide caregivers with emotional support, informational support, and enhancement of coping skills. These groups can be led professionally or by lay members. The emphasis is on sharing of feelings, experiences, coping strategies among members. Psychoeducational interventions with a social learning orientation emphasize provision of information by professionals and skills to better enable caregivers to meet their needs. Psychoeducational interventions consist of cognitive information, self enhancement and behavioral management skills. Clinical or direct service interventions are treatment oriented and they include such things as counseling, therapy, respite, day hospital and general psychological interventions. However, some interventions may encompass all these interventions and it can be difficult to distinctly differentiate them in practical situations. For the purpose of this paper, these intervention studies will be discussed according to designs utilized viz. descriptive and clinical trials intervention studies.

## Descriptive Studies

The studies evaluated mainly used non-standardized generally open-ended questions and consumer self reports to assess the effectiveness of the intervention modalities employed. Generally the respondents were asked to state what they liked best about the group or what was most helpful. This is a very subjective evaluation and as a result their results should be interpreted with caution.

Schmidt et al., (1985) reported a detailed experience of caregivers of Alzheimer's disease caregiver support group (N = 10). All were from the middle class, could make active contributions and were articulate. The attendance was consistently high, indicating that the group members were gaining something from the support group, or they had some forum where they could ventilate their frustrations and release whatever tension they were experiencing. The good attendance for this group might have been influenced by several factors. Definitely the social class and the level of education played an important part in influencing participation.

Boyd, McGill, and Faloon (1981) described a model program using family as the essential community support instituted at the University of Southern California Medical Center together with University of California at Los Angeles. Family sessions (N =30) were conducted in the homes to reduce the incidence of unkept appointments. Sessions included education about illness, course, treatment , communication training , structured problem solving and other behavioral strategies. It was found that education on the nature of schizophrenia and medication constituted powerful interaction intervention. Medical compliance improved and criticisms and hostility towards the patient reduced. It was not clear how the program was evaluated for its effectiveness. However, it appears that patient recidivism was used as an evaluation criteria because from the thirty families only three patients were rehospitalized. The inclusion criteria might have influenced the results because families were mainly middle class.

Follow up of families in their homes has inherent advantages because it reduces the cost of travel on the family. The program is also tailored according to the specific needs of that particular family. However, more staff is needed to effectively conduct home visitations. The catchment areas for the mental health providers also need to be manageable. In situations were there is inadequate staff, inadequate transportation, and large catchment areas, home visitations can be problematic.

Research in the UK and several other countries indicate that Expressed Emotion (EE) that is, hostility and critical comments when reduced can drastically improve the rehospitalization of the mentally ill. Leff et al., (1990) found that hostility and critical comments by relatives of the mentally ill in India had reduced drastically by the end of a two year follow up. The authors noted considerable acceptance of both negative and positive symptoms that relatives exhibited. The relatives concerned seem to have come to terms with the fact that the patients suffer from an illness and consequently no longer blame them for difficult behavior. They also seemed to have learned not to be provoked by he mentally ill relative's irritability to becoming angry. Comparing this Indian families with the Western families, they showed a significantly lower proportion with high-EE ratings ($p < 0.005$). Similar findings were found in other studies which also compared the EE ratings in western and non-western countries (World Health Organization, 1979). Thus, these findings suggested that the better outcome for the schizophrenia in North India might be partly attributable to the greater tolerance of relatives for the illness. It can be concluded that the more the families understand mental illness the more they will be able to cope with their mentally ill relatives.

In a day care center for patients with Alzheimer's disease, Sands and Suzuki (1983) reported that respite care improved patient cognitive functioning and emotional status. Family members also reported gains of relief and emotional support because their relative did not have to be institutionalized but still received good care. In addition, the cost of care both emotionally and financially was manageable. The care to their relatives was good and was provided at minimal cost. This indicates that respite care can be helpful in providing an opportunity for afflicted persons to participate in a psychosocial environment which can be emotionally therapeutic. In the long run, both the patient and the relatives benefit because this provides some respite for the families. However, this arrangement may only work in certain settings and for certain families who may be committed to taking the ill person to the day care center. Therefore, thorough family assessments need to be done to capture the specific needs of families.

Hatfield (1981) assessed the potential of self help movement in assisting families of the mentally ill cope with their disabled relatives by examining self-help organizations and observing the national mental health alliances. The self groups were categorized into three namely: independents, which were organized by relatives of patients (N = 34), affiliates, which were affiliated with the state mental health associations and mental health centers (N = 20), and Huxley, which were associated with the American Schizophrenia Association, a division of Huxley Institute for Biomedical Research (N = 16). The organization, objectives, activities, and strengths and weakness were descriptively examined. The affiliated groups tended to be smaller in membership. The primary objective of these groups was to provide emotional support, education, and consumer advocacy for the families. Overall the groups lacked funds, clout and still suffered stigma from the communities. There was reported lack of response from the mental health professionals. On the whole, the families were able to ventilate their feelings and learn more about mental illness from others. However, most family members complained that the groups did not seem to involve the patients. Although the self-groups do not target specific individual family needs, they nonetheless assist the families to cope with mental illness.

In a group treatment for the parents of the adult mentally ill, Mclean, Geer, Scott, and Beck (1982) found that educating the families about mental illness and equipping them with skills to manage their sick relatives changed them. Some family members were able to communicate better with their ill relatives and they could set boundaries for them and relinquish their protective behaviors towards the patient. Parents reported that they were helped to separate from their adult children and they regained and rebuild their family esteem. In addition, the groups provided a forum for education of other community leaders. This group mainly targeted parents whose children were already chronic. Perhaps the groups should now target parents before their children reach a chronic stage to see whether this will be effective in the preventing chronicity.

## Clinical Trials of Family Intervention Studies.

It is important that the different intervention modalities be compared to identify their effectiveness in assisting the families to cope with their mentally ill relatives. Kane, DiMartino, Jimenez (1990) in their quasi-experimental, nonequivalent study sought to evaluate the efficacy of two intervention modalities by comparing psychoeducation (N= 24) with support groups (N = 25). The psychoeducational intervention consisted of interactive instructional activities that included information concerning the symptoms of schizophrenia, communication training, and home management strategies. The support group on the other hand was basically a lay self- help intervention.

Family members were assessed before and immediately after the group intervention using a structured questionnaire which was composed of knowledge acquisition, perceived social support, distress and inability to cope with the patient's problems, depression and satisfaction. Knowledge acquisition was measured by Mental Illness Questionnaire (Liberman, Falloon, & Aitchison, 1984) which has a Cronbach's alpha, of .83 for this sample. Perceived support was measured by the Perceived social Support questionnaire (PSS) developed by Prociodano and Heller (1983) with a Cronbach's alpha of .92 for this sample. The Family Questionnaire (Barroclough & Tarrier, 1985) measured distress and inability to cope. The Cronbach's alpha was .92 for distress and .94 for inability to cope. The depression subscale of the Symptom Distress checklist (alpha .91) was used to measure depression. This scale consists of 13 items and a 5-point Likert scale was to indicate how often the individual experienced various symptoms of depression. Lastly, satisfaction was measured by the CSQ-8 with an alpha of .92 for this sample.

The T-tests between the two groups at pre-test showed no significant differences ($t = 3.14$, $p < .01$ and $t = 3.37$, $p < .01$ respectively). One-way analysis of covariance was used to test the treatment effect on posttest means. The analysis showed that the psychoeducational group reported fewer symptoms of depression ($p < .05$) and rated their experience with greater satisfaction than the support group ($p < .01$). Both groups improved significantly on their knowledge gain ($p < .001$). The psychoeducational participants rated the quality of information they received as excellent (74%); and 94% said that they received the kind of help they wanted.

From these findings, it can be concluded that psychoeducation seems to be a more powerful and effective intervention strategy than support groups. It does also seem to meet the expectation of the family members. This finding can be valuable, especially to those settings where there are inadequate resources because short term psychoeducation programs can make an impact in improving families' understanding of mental illness and their abilities to provide care. However, without experimental studies, it can be difficult to say exactly which intervention is more effective than the other. More research needs to focus on these designs to prove cost-effectiveness of these interventions. These findings should be interpreted with caution because the Cronbach alphas for the measures were somewhat high ranging from .83 - .94. While it is desirable to have reasonably high alpha levels, alphas of .90 and above may indicate problems of redundancy in the units measurements and this can lead to false understanding of the phenomenon being studied.

Similarly, Posner, Wilson, Kral, Lander, and Mcllwraith (1992) in a randomly assigned family members to a psychoeducational support group (N = 28) or to a control group (N = 27). The recruitment of volunteers for the study was made through a referrals from psychiatrists at four hospitals in Winnipeg. Each patient was asked to name an individual family member with whom he or she had closest contact. Family members in the experimental group had significantly higher scores on schizophrenia knowledge (F = 4.90, p < .033). Compared to the scores obtained at the initial assessment, the group participants had significantly higher scores immediately following the program (F= 11.66, P < .001) and at six months follow up (F = 6.10, p < .02). Concerning consumer satisfaction, the experimental group had significantly higher scores than the control group (F = 6.25, p < .017). However, differences between the groups in terms of family satisfaction was not statistically significant. Therefore, these results should be interpreted with caution because they are based on self report inventory. Furthermore, the results are based on comparisons of relatively small biased samples. Furthermore, patients identified relatives whom they wanted to take part in the study.

Parallel to the aforementioned studies, Glick, Clarkin, Haas, and Spencer (1993) tested the statistical significant of an inpatient family intervention for hospital practice. Hospitalized patients and their families ($N= 169$) were randomly assigned to a psychoeducational inpatient family intervention or a comparison group. Patient and family outcome measures were assessed at admission, discharge, six and 18 months after admission. Chi square analyses of statistically differences in outcome suggested that inpatient family intervention was effective for certain patients ($p < .05$). There were significant differences between patients in the family intervention group and the comparison group who achieved clinically significant change ($p < .002$). Jacobson et al (1984) define clinical significant change as "the extent to which therapy moves the patient outside the range of the dysfunctional population and into the range of functional population" (p. 133). However, the study did not assess the functional capabilities of these patients in order to demonstrate the significant change.

Poggenpoel (1993) calls for a re-evaluation of psychiatric services in South Africa and a change in health policy from a medical model to a public model approach, which will include provision of care for all people of South Africa. This change in health policy sees the community as being the responsible for providing care. This has been necessitated by several factors such as nursing costs in psychiatric care, high relapse rate of patients treated on outpatient basis, severe shortage of professional manpower in psychiatric services, detrimental effects of prevalent violence in the communities.

The health for the people by the people means that the responsibility will be on the communities to participate in providing health care. For community psychiatric care to be effective, more attention will have to be given to mobilizing natural resources including personal and social networks within the community to assist in the primary, secondary, and tertiary prevention of mental illness. The paper identifies the following as community support systems: the family, church, traditional healers, and lay workers. This challenge therefore, calls for a better understanding of the positions and situations of community network support systems by studying families who are already involved in the care of their relatives. It is believed that the information elicited will provide a better basis for better planning of community mental health services.

In her evaluation study, Uys (1994) reports on two strategies which were implemented in the service to black patients - psycho-education groups and social skill training. The implementation of the strategies was evaluated by looking at feasibility and effort, and their effectiveness was assessed by measuring functional status, symptom improvement and duration and frequency of hospitalization. It was found that both strategies could be implemented although with problems. These related to the physical facilities in clinics, the lack of adequate training of nurses in these techniques, and the inadequacies of community resources. Hospitalization was used both as pre and post test because none of the patients were hospitalized during the study. Skills teaching was found to influence functional status positively. The study showed that psychiatric community clinics should be organized to include psycho-social rehabilitation strategies. These strategies are generally effective and can be implemented if there is a rehabilitation philosophy in service.

## Summary Review on Intervention Studies

By and large, the research designs utilized in the studies on interventions were quite diverse. They ranged from descriptive reports to clinical trials. The randomized clinical trials were utilized mostly to test psycho-educational interventions using pre and post test evaluations. These studies yielded much stronger findings that can be accepted with much greater confidence than findings of descriptive studies, which were mainly used to assess the consumer satisfaction. The interventions were mainly targeted to primary caregivers and not to all the family members. Since others, especially the siblings can be adversely affected by the situation, future research should focus in involving all members of the family to assist them cope with the situation.

In addition, the samples were too small and predominantly drawn from middle class subjects like in the above reviewed studies about caregiver burden. Thus, the studies did not represent a wide range of socio-economic statuses and ethnic groups. An understanding of how these other groups fare is essential in order to assist health providers to plan appropriate interventions. Furthermore, these small samples limit the statistical analyses that can be undertaken. For example, the usage of multiple regression analyses which are mainly big sample techniques which can give specific contribution of each variable in the study may be restricted (Glantz & Slinker, 1991). The small samples also limit the generalizability of the findings generated by these studies to the general population or non-white cultures.

Overall, findings converged and strongly demonstrated that subjects gained knowledge about mental illness. However, most evaluations measured the effects of psychoeducation immediately after the intervention. It would be interesting to know more long term effects of these interventions. That is, over what length of period is the knowledge sustained. This would assist health professionals in planning of subsequent interventions to maintain the desirable knowledge and the motivation levels of the families.

The intervention studies used standardized measures, open-ended, and close ended questions which required self-reports to examine group outcomes. Evaluating the effectiveness of a program using self-reports can be problematic because of lack of objectivity. The criteria that were used for selection of the samples were biased because most participants were selected through institutions and this excluded those who do not utilize these institutions. Therefore, participants through these routes are well connected to the peer support or mental health services (Chafetz & Barnes, 1989). Tessler, Killian, and Gubman (1987) asserted that, the most isolated and stigmatized family members may be the hardest to include in research studies. These ways of subject recruitment in some ways may have influenced the findings obtained in the studies for example, the desirable and positive outcomes of interventions employed in some studies. Future sample selection should strive to include groups of people from different ethnic, socio-economic backgrounds, and non-western contexts such as Botswana to determine what similarities and differences may exist. Overall, findings have provided some ideas on how intervention programs for improving the family caregiving situations can be designed implemented and evaluated.

## Conceptual Framework

### Community or Collective Participation

Community participation has been selected to serve as a template for the this study. Community participation is the cornerstone of primary health care (PHC) advocated by the World Health Organization (WHO) to reach the goal "Health for All by the year 2000" (WHO, 1978). This Alma Ata declaration asserted that health is a fundamental human right and individuals must participate in their own health care. The model encourages collective and cooperative responsibility. The caregiving situation is seen as a cooperative and collective endeavor.

The belief that the individual, family, and community are partners in the processes of seeking, promoting, and maintaining health is upheld. Partnership implies equity in relationships; and equity in relationships implies empowerment. The results of the pilot study on the caregiver support needs indicated a need for empowerment and collective determination of the family caregivers to address the societal problems of the mentally ill in the community in Botswana (Seloilwe, 1995). Community participation is grounded in partnership and unity, self-reliance, consultation and development; that is, if people come together and work together, they may be able to deal with their problems. These principles are fundamental to communitarianism embedded in traditional Tswana society and are upheld as providing guidance to the way of life of a people of Botswana.

Community participation is seen as a social process that involves partnership in the identification of needs and making decisions to establish mechanisms or ways of how to meet these needs (Rifkin, 1988). Community participation can occur at different levels such as the individual, family, and community.

Viewed from this perspective, community participation ties in well with the epistemological and theoretical tenets of grounded theory approach, such as symbolic interactionism, which address individual, family, and community levels of analysis. Grounded theory method, like all qualitative methods, seeks to understand phenomena from the perspectives of the participants. One of its main canons is anti-determinism. That is, the actors are seen as having some means of controlling or at least influencing their destinies by their responses to conditions (Strauss & Corbin, 1990a). The authors further state that the actors are able to make choices according to their own perceptions and attributions of meaning, which are often accurate about the options they encounter. Both symbolic interactionism and community participation share this stance. Strauss and Corbin (1990a) argue that grounded theory seeks to uncover relevant conditions as well as determine how the actors respond to the changing conditions and to the consequences of their actions. The researcher's responsibility is to catch this interplay. This interactive approach is necessary whether the focus of a study is at individual, family, or community level.

### Levels of Participation

The WHO support Group (1991) identifies three levels of participation: 1) Passive, where the health provider is in control and has a dominant role than the client; 2) Consultative, where the health provider and the clients work together as partners in identifying the problems in the community; and 3) Initiated, where the clients take initiative in the identification of their needs, propose plans to meet these needs, and implement the proposed plan. Community participation is influenced by the role of the health provider. Rifkin (1981) described the role of the health provider in three approaches: 1) medical approach in which there is control by the provider; 2) health services approach in which mobilizes the people to take active part in the delivery of health care; and 3) community development which aims at community involvement of the people in the decisions about how to improve their health.

### Benefits of Community Participation

Community participation in social support will assist in the grounding of the phenomenon in the actual situation rather than assumed. In addition, community participation encourages collaborative endeavor in addressing the problems of the caregivers. Dressler (1993) stated that collaborative research informs the investigator about the lived experiences of the people and further uncovers new ways of understanding the phenomenon. It also provides power to the community to persuade policy makers to provide needed resources to address the problems.

## Assumptions

Any conceptual model entails delineation of assumptions, concepts, and relationship statements that link these concepts (Stewart, 1990). The assumptions that underlie this frame of reference are as follows:

1. Persons are social, rational, perceiving, and thinking beings
2. Persons have unique knowledge base derived from their personal experiences
3. Persons as biopsychosocial, cultural, and spiritual beings have the right and responsibility for optimum health.
4. Persons are competent to help themselves and others.
5. Persons have the right to independent choices and control.
6. Persons' perceptions of support from their social environments may differ from perceptions of nurses and network members.
7. Persons must fully participate either individually or collectively to mobilize support within their communities/environments.
8. Persons have the right to self determination.
9. Persons must be seen as equal partners in care by nurses and other health providers who should only provide guidance and not dictate.
10. Lastly, the communities must be seen as a source of diverse forms of support.

Bearing in mind these basic assumptions, the families will identify what they perceive their support needs to be; the strategies they envisage suitable to addressing these needs; development of plans to meet these needs; implementation of the designed plan and evaluation of the effectiveness of the plan. However, the study will only be limited to the identification of or the perception of support needs of the family caregivers and the strategies that can be employed to mobilize support.

## Cross-cultural Applicability and Utility of the Research Findings

The literature thus far strongly suggests that families of the mentally ill do experience burden. The experiences of the families however, may differ depending on several factors such as living arrangements, socio-economic status, perception and availability of the necessary support and what families identify as appropriate intervention modalities. Although the current research literature has laid some foundational work in the perception of the magnitude of the situation of caregivers, there are still some gaps and inadequacies that exist in this body of literature.

The areas still deficient include the differences in the conceptualization of concepts of burden and social support which has led to measurement issues such as determining which components to measure and whether to use objective or subjective approaches and how to define the units of analysis. Although both qualitative and quantitative methods were used, there is still need to further understand how other non-western cultures such as Botswana perceive the caregiver situation. The understanding of caregiver situation in non-western cultures warrants a qualitative inquiry. The instruments that have been used to measure burden, social support and intervention modalities were mainly developed for the particular cultural groups they were used within the US. It cannot be assumed that these instruments can be applicable and appropriate or relevant in other settings such as Botswana. Vega and Rumbaut (1992) assert that the creation of culturally relevant measures requires knowledge about that particular cultural group such as the socio-demographics, language, customs, and values. Therefore, it is unlikely that these instruments can be transferred and utilized in different cultural settings. It becomes imperative that culturally relevant and specific measures be developed.

Although the overall findings yielded by these studies have laid some foundational work in the understanding of family burden, and what interventions are assumed to be effective in ameliorating these problems, there were no indications whether these families actually desired these interventions. It is essential to determine what families think about interventions that would be more helpful in their own geographic, social, and cultural context. It is important to get the perspectives of the families because they may desire different interventions depending on their needs. This heightens the need for more family perspective research because families are different and have unique experiences. For example, the pilot study conducted in Botswana elicited that basic needs of the families were more central in comparison to their American counterparts who needed more information about the illness and emotional support. There was a clear distinction between the two groups in the way they conceptualized their support needs. Therefore, interventions preceded by a thorough family assessment may begin to address the problems of the families in a more specific way.

Several studies focused on the primary caregivers, and samples reviewed were small, middle class, and non-random. Also units of analysis in these studies were predominantly individuals. There is a need to extend research in this area to other ethnic groups in order to elicit how mental illness affects these families. It is believed that there is still much that can be learned about the interaction of mental illness and the family. Research also needs to change its focus from the primary caregiver to understanding the role of multiple caregivers such as siblings, spouses, and children of the mentally ill especially if these other groups also live with the mentally ill. This is particularly important in the case of Botswana because families are extended and thus consist of multiple caregivers. The roles and contributions of multiple caregivers have not been addressed by the current research. The roles and contributions of each member of the family and how these impact on the caregiving situation need to be understood. The understanding of these roles will also clarify the role gender plays in multiple caregiving. For example, the roles and the contributions of males in caregiving in multiple situations are not known. Males have been studied only as solitary caregivers and no knowledge exists of male contribution to multiple family caregiving.

## Research Questions

The main aim of this study was to understand the caregiving situation of families with a mentally ill relative at home in Botswana from the perspective of the families themselves. The questions that study addressed stemmed from the inadequacies identified in the literature and limited information that exists in Botswana on the subject. The research questions were as follows :

- What were the perceptions of families about giving care to mentally ill relatives in Botswana?
- What were the experiences of the families in caring for a mentally ill relative at home?
- What were their support and available support interventions?
- How have these support interventions been appropriate and relevant in addressing the family caregivers' needs?
- What sectors (formal and informal) were instrumental in assisting the families to cope with the caregiving situation?

- What resources were available at community level to support the family caregivers for the mentally ill?
- What were the roles and contributions of each family member in the caregiving situation?

## Definition of Terms

1) Family refers to a group of people who have a common ancestry. Thus all known living relatives constitute an extended family. These people may not necessarily have a common abode. Members share a common culture, economic resources, and a moral responsibility for the welfare of one another. Such people, though commonly biologically related may include those who came into the family through adoption and association.

2) Family caregiver is anybody who resides in the community with a mentally ill person and assumes or shares responsibility in the care of the mentally ill person. The caregiver may or may not necessarily live with the mentally ill in one household and may or may not be a blood relative.

3) Caregiving situation encompasses all social and material necessities involved in the provision of care to mentally ill persons in the community.

4) Support systems include a variety of the sources of help which can be material, non-material, informal (relatives, friends, neighbors), formal (health professionals, social workers, and community development workers) and organizations such as churches and communities.

5) Caregiving responsibilities include any services such as household chores, instrumental help, financial assistance, decision making or any tasks that are performed in the caregiving situation.

6) Caregiver experience is the living through or personal involvement in the care of the mentally ill.

7) Caregiver perception refers to the awareness and understanding of the caregiving situation.

8) Key informant is that member of the family who was considered to be in charge of the caregiving situation and spoke on behalf of other members but was not necessarily the sole provider of care.

The grounded theory method was selected to address the aforementioned research questions. The following chapter gives a brief description of the method, techniques, issues, and concerns that were encountered during the research process.

# CHAPTER III: METHODOLOGY AND STUDY DESIGN

## Introduction

This qualitative study utilized a grounded theory approach to examine family psychiatric caregiving in Botswana. The study's goals were twofold: 1) to understand and describe the caregiving situation of families of relatives with mental illness at home or in the community; and 2) to contribute to evolving of theory about family caregiving of the mentally ill that is grounded in the ways the families conceptualize their caregiving situations in Botswana. A qualitative methodology was appropriate to answer these research questions. This study addressed the following questions: 1) What were the perceptions of families in Botswana about giving care to mentally ill relatives? 2) What were the experiences of the families in the care of a mentally ill relative at home? 3) What were their support networks and available support interventions? 4) Have these support interventions been appropriate and relevant in addressing the family caregivers' needs? 5) What sectors (formal and informal) were instrumental in assisting the families to cope with the caregiving situation? 6) What resources were available at the community level to support the family caregivers for the mentally ill? 7) What were the roles and contributions of each family member in the caregiving situation?

## Study Design

Grounded theory was specifically chosen for its flexibility in data collection and exploration of concepts and for its techniques of data management and analysis. In addition, the lack of substantial research data in Botswana on this subject, and the status of current literature on caregiver burden and support warranted further research in this area. As discussed in the review of the literature, the empirical knowledge base is inadequate in non-western countries to explain family caregiving situations for the mentally ill, particularly in extended family contexts where multiple or collective caregiving exists.

A fundamental assumption in qualitative research is that the subject's perspective on the phenomenon of interest will unfold in the interviews and research as the subject views it, not as the researcher views it (Marshall & Rossman, 1989). Thus questions are focused on eliciting the subjective experiences of family caregivers for the mentally ill to better understand their perceptions, experiences, demands, attitudes, feelings, beliefs, values, their strengths, and support systems that sustain them in their caregiving endeavors.

Qualitative inquiry seeks to inform with words. From this naturalistic perspective, knowledge is subjective and requires that discourses consider the possibility of multiple simultaneous realities (Moccia, 1988) in the situation of concern. Fundamental to this naturalistic view is the precept that in order to understand social phenomena, it is necessary to gain access to the meanings people hold for things, because it is from these meanings that they construct their own personal views of realities and then act toward others based on these meanings.

The grounded theory method is a "qualitative research method that uses a systematic set of procedures such as coding, theoretical sampling, memos and diagrams to develop an inductively derived grounded theory about phenomena" (Strauss & Corbin, 1990a, p. 24). It also seeks to describe processes, patterns, and to build theories about the day to day lives of people. Such theories are grounded in the data collected from these people about their life experiences (Strauss & Corbin, 1990b). This characteristic of grounded theory distinguishes it from other qualitative approaches such as ethnography and phenomenology whose main aim is to describe and understand phenomena rather than theory development. The grounded theory approach is unique in that its primary aim is to generate abstract theoretical formulations and to discover the basic social processes of a particular phenomenon under study (Strauss & Corbin, 1990a). The "development of theoretically informed interpretations is the most powerful way to bring reality to light" (Strauss & Corbin, 1990a).

The grounded theory analysis was used to generate themes which were grouped together into sub-categories and categories about the meanings and perceptions of caregiving situations, demands, and social support. Grounded theory was adopted because very little is known about this phenomena in Botswana. Sandelowski (1986) argued that qualitative methods are relevant and appropriate for investigating phenomena about which little is known.

## Setting

The study took place in Botswana. An urban and a rural area were selected as the micro settings for this study in order to compare and contrast caregiving experiences of urban and rural populations. It was strongly believed that these experiences would differ because of the different influences of the cultural, economic, and socio-political factors in these contexts. Gaborone was selected as the urban area and Molepolole as rural (refer to figure 1).

### Urban Setting

Gaborone is situated in the south eastern part of the country and has a population of about 133,791 (Population & Housing, 1991). There were several reasons why Gaborone was selected: 1) There is a psychiatric clinic attached to the main hospital, Princess Marina Hospital (PMH); which serves a catchment area that includes Gaborone and neighboring villages; 2) Due to limited research funds and time frame, it was feasible to select a place that was within easy reach in order to minimize expenses.

The specific locations in Gaborone were not selected per se, but were determined by where the mentally ill and their relatives lived. A great number of the mentally ill and their relatives resided in places such as Broadhurst Maruapula, Metro, and No Mathata, Tshweneng, Bontleng, White city, and Old Naledi. These areas were mainly low income and housing here is subsidized. This subsidized housing scheme is known as the Self Help Housing Agency (SHHA).

Due to the exorbitant cost of land in the urban areas, the Botswana government devised a low income housing scheme for underprivileged urban dwellers (SHHA). The SHHA housing scheme was initiated around the 1980's as an effort to provide housing for the grossly underprivileged city dwellers who could not afford to purchase state land. These were people who migrated from the rural areas to the cities in search of employment and settled as squatters. The scheme is heavily subsidized by the city and town councils. Its main objective was to assist the low income urban dwellers to own homes. The councils contribute 50% and the person the other 50%. The housing scheme however, is not without shortcomings. Its main limitation is that a person ought to be employed in order to fulfill her/his contribution. Low income populations are normally characterized by high unemployment rates and very often they are restricted from acquiring a home or some property.

## Description of the Households in SHHA

The minimum structure that can be supported by this scheme is a two-roomed house. However, those who have the means are free to build a house of their choice. The SHHA typical household may not have running water, indoor bathroom and toilet, kitchen, and electricity. The toilet is built separately outside and has a septic tank that is emptied by the city council sanitation department when need arises. There is a public water stand within a fifty meters radius where people draw their drinking water.

One feature that typifies the households is that, although the yards are very small, almost every household has rooms for rental. In most instances the yard is composed of the main household and its members and the people who rent the rooms. The lodgers or renters may or may not take part in the caregiving of the mentally ill person.

### Social Resources and Services

Usually the social services available to the families in these areas include the nurses, social workers, community development workers, the police, and the district commissioner. These departments will usually respond to any emergencies or crisis situations. The families usually utilizes those services that are within easy reach and those that respond promptly to their needs. The general health facilities also respond to crises however, their response may be slow due to factors such lack of transport and shortage of staff. There is only one psychiatric clinic in Gaborone and policy trend is to include the care of the mentally ill in other primary health care services. The mental hospital is about 70 km from Gaborone. Therefore, it is often difficult to transport patients promptly for hospitalization.

### Risks Factors in the Environment

The social context of the neighborhoods in SHHA is characterized by high unemployment, crime, and substance abuse. The localities have "shebeens" (people who earn their living by selling beer in the home) who may or may not make local brews. The home made brews are the most dangerous because they are a mixture of many compounds and they contain very high levels of alcohol. These include but are not limited to *khadi, mokoko o nchebile, laela mmago* (literally meaning bid your mother farewell). The connotation here implies that the person may die after drinking this type of brew and that is just how dangerous it is. The other substance that is highly abused is dagga or marijuana. The social processes surrounding the use of such substances is that people sit around and share, e.g., passing a bowl of beer around or passing a puff around. Therefore, people without any money to purchase alcohol or dagga, would still get them anyway. Also, the mentally ill are more susceptible to risks in the neighborhoods such as assaults and injuries which may lead to death.

## Rural Setting

Molepolole, with a population of 36,928 people (Population & Housing, 1991), was selected as a rural setting and is situated 50 km west of Gaborone. This village was chosen because it has a psychiatric clinic and because of its proximity. A village setting is different from that of a city. The location of households are not determined by the means but by the clan that one belongs to and if land is available. Unlike in the urban area, land is free and belongs to the tribe and administered by local authorities. The yards are quite big with an average surface area of about 1600 sq. meters. The households may be modern or traditional. In a traditional set up there may be several huts in the yard which may be designated according to use such as bedroom, storeroom, or kitchen. The huts are thatched. The traditional Tswana societies did not have sitting rooms. The hut used as a kitchen was often times used as a sitting place if it were cold or raining. Otherwise people would generally sit outside.

### Social Resources and Services

Like in the city, the social services that are often available to families of the mentally ill includes nurses, community workers, district commissioner, police and prison's departments. The difference is that they are very limited. These departments mainly assist with transportation in times of crises and emergencies. The caregivers usually utilize and know departments that respond promptly to their needs.

### Risk Factors in the Environment

The risks in the environment include those ones found in the city, but they may be of a lower magnitude. The crime rates in the rural areas are somewhat lower than those in the cities in Botswana. However, the mentally ill are still exposed to hazards such as alcohol abuse and dagga (marijuana) smoking. Likewise, the socializing process involves sharing as already mentioned. The mentally ill who wander around at night are also vulnerable to assaults, injuries, rape, and the danger of being killed.

## Sample, Sample Size and Sampling Procedure

## Recruitment of Informants

### Sample for Individual Interviews

Caregivers included in individual interviews lived with and cared for the mentally ill person, for at least a year. The family caregivers were recruited through psychiatric outpatient clinics which served as focal points of contact with the families. The mentally ill persons were asked to identify a family member who they considered to be taking care of them. When a relative was identified, the person was contacted by the investigator and recruited to participate in the study.

The nurses were also utilized to identify families they thought would be informative. I also accompanied the nurses during their home visits to see where families resided and for possible recruitment in the study. In Molepolole, the nurses assisted by drawing a list of the mentally ill persons with their clan name or *kgotla*. Then somebody from the clinic accompanied me to show me the *kgotlas* and where the families lived. These were the most feasible ways to select the sample given the time frame of this research.

These procedures resulted in an individual sample composed of thirty individual caregivers (N = 30). These key informants were persons considered to be in charge of care in that family who met the inclusion criteria.

### Sample for Group Interviews

For the group interviews, members of the group may not have resided with the ill person, but were involved in the care by making certain decisions pertaining to care. The sample was composed of four groups (N=4), two groups in the rural area and two in the urban area. Procedures that were utilized to identify the individual informants were used for the groups to identify the head of these families. This person was approached first and, if he/she agreed to participate in the study, he/she was requested to assemble a group for an interview.

## Socio Demographic Characteristics of Caregivers and Recipients.

### Demographic Description of Caregivers

A convenience sample of thirty family caregivers (N= 30) and four family groups (N=4 ) was used to examine the family psychiatric caregiving situation in Botswana (refer to table 3). The sample was drawn from an urban area ($n$= 16) and a rural area ($n$=14). Caregivers in this sample varied in terms of age, sex, income, educational level, and duration of care. The duration of care ranged from 1-26 years. Most caregivers in this sample had given care over quite an extended period of time.

The age of the caregivers ranged from 21 and 74 years; 67% (n=20) of caregivers were 50 years and above and this is consistent with previous research in caregiving literature (Howard, 1994). Males constituted only 13% (n=4) and females 87% (n= 26). This seems to be universal that most caregivers are women. The educational level of caregivers was found to be generally low; 30% (n=9) never attended school; 40% (n= 12) attended the primary level; 7% (n=2) secondary or high school, and 3% (n=1) had university education.

The income level was also low. Only 37% (n=11) had regular income. However, this was found to be far too inadequate to maintain the whole family. The location of the households, especially in the urban area to some extent, also indicated the socio-economic level of the families. Most urban caregivers (n= 15) lived in the low cost housing plan which is mainly a self-help assisted housing scheme (SHHA). However, this may not necessarily give an accurate picture but it gave some indication of their socio-economic status. It was not easy to use location of household as an indicator of the socio-economic status of the rural sample because the location of residence in the rural areas is organized differently as already described.

The analysis of the socio-economic status in the rural area looked at different indicators since income did not provide a good indicator. Rather, the family's socio-economic status was assessed in terms of whether it was able to produce enough food for its members. Most of the rural caregivers 71% (n=10) were farmers e.g., ploughed or reared cattle or traded for money, crops, or cattle. Only 14% (n=2) were employed and 14% (n=2) lived as destitute families.

Although one person was interviewed, the households composed of several people who formed members of that family. The person who was interviewed was considered to be a key informant and in charge of the overall caregiving situation. This person did not do all the work by herself/himself. There were others who shared in the care. This living environment offered some respite to the members of the family. Most families were extended in nature with an average of six members. Nuclear family structure was rare in this sample. Of the thirty individual interviews conducted, only two families were nuclear. The extended families were composed of parents, children, grandchildren nephews, nieces, and grandparents (refer to Chapter four for genograms of these families).

### Relationship of Caregiver with the Ill Person

Parent caregivers (mothers and fathers ) constituted 60% (n= 18), grandparents 6% (n= 2), daughters to the ill person 13% (n= 4), and spouse 10% (n=3). Others included close relatives such as nieces and sister in law 10% (n= 3). The relationship to the ill person was considered important because it assisted in understanding the extent of commitment and the degree of the sense of responsibility for the ill person. At least 30% (n= 9) of the sample had a history of mental illness in the family. The relationships of people who had mental illness were a parent, grandparent, sibling, aunt or uncle.

### Preferred Health Care System and Type Used

All the caregivers reported that they have, at one stage, taken their ill relative to a traditional healer. However, 83% (n=25) reported that they used western health care. Thirty three percent (n= 10) preferred both western and traditional, 53% (n=16) preferred western, and 7% (n=2) preferred traditional. These findings indicate that seeking alternative means of treatment is still widespread among the caregivers of the mentally ill in Botswana.

Table 3: Demographic Profile of Caregivers

| Characteristics | Number (N = 30) | Percentage |
|---|---|---|
| Age | | |
| 21 - 30 | 4 | 13 % |
| 31 - 40 | 3 | 10% |
| 41 - 50 | 8 | 27% |
| 51 - 60 | 5 | 17% |
| 61 = 70 | 10 | 33% |
| Sex | | |
| Female urban | 13 | 43% |
| Male urban | 3 | 10% |
| Female rural | 13 | 43% |
| Male rural | 1 | 3% |
| Educational level | | |
| No education | 9 | 30% |
| Primary | 12 | 40% |
| Secondary | 2 | 7% |
| University | 1 | 3% |
| Regular income | | |
| yes | 11 | 37% |
| No | 19 | 63% |
| Duration of care | | |
| 1 - 5 | 13 | 43% |
| 6 - 10 | 9 | 30% |
| 11 - 15 | 4 | 13% |
| 16 - 26 | 4 | 13% |

Table 3: Demographic Profile of Caregivers (continued)

| Characteristics | Number (N = 30) | Percentage |
|---|---|---|
| **Religion** | | |
| None | 12 | 40% |
| Christian | 7 | 23% |
| Zionist | 4 | 13% |
| Evangelic | 4 | 13% |
| Other | 3 | 10% |
| **Relationship** | | |
| Grandparents | 2 | 6% |
| Parents | 18 | 60% |
| Spouse | 1 | 10% |
| Daughters | 4 | 13% |
| Other relatives | 3 | 10% |
| **Health care used** | | |
| Western | 25 | 83% |
| West/traditional | 7 | 23% |
| **Preferred H/Care** | | |
| Western | 16 | 53% |
| Traditional | 3 | 10% |
| Both | 11 | 37% |
| **Marital status** | | |
| Married | 8 | 27% |
| Divorced | 1 | 3% |
| Widowed | 7 | 23% |
| Single | 13 | 43% |

### Demographic Description of the Recipients.

Table 4 summarizes the demographic characteristics of the recipients of care in this study. There were 36 recipients of care, including 16 females (44%) and 20 males (56%). The number of recipients exceeded that of caregivers because some families had more than one mentally ill person. For example, one family had five (5) and other had three (3) mentally ill persons. The sample of recipients from the urban area was composed of 53% females (n=9) and 47% males (n=8). The rural sample on the other hand had 37% females (n=7) and 63% males (n=12). The age ranged between 18 and 57 years with a mean age of 40.66. More than 50% of the recipients were between the age of 18 and 47 years old; in contrast, 50% of caregivers were above 50 years.

Their diagnosis was predominately schizophrenia 97% (n= 35) and 3% epileptic (n= 1). Although this was a limited sample, a high prevalence of schizophrenia confirms it as the major psychiatric disorder (see Table 1 for common psychiatric morbidity in Botswana). Lack of adherence to treatment was higher in the urban area 76% (n= 13) than the rural area 26% (n= 5). However, only 18% (n= 3) of the urban and 5% (n= 1) of the rural recipients had been readmitted into hospital in the last six months to one year. The duration of illness ranged from 5 - 26 years, with more than 50% of the recipients having had the illness for an average of 6 years, demonstrating a fair assumption of chronicity.

Comparatively, the recipients had a higher level of education than their caregivers, with 28% (n=10) having attained high school and 3% with a university degree. About 82% (n=14) of the urban recipients had previously held employment as compared with only 26% (n= 5) of the rural population.

Table 4: Demographic Profile of Recipients

| Characteristics | Number (N = 36) | Percentage |
|---|---|---|
| **Age** | | |
| 18 - 20 | 2 | 6% |
| 21 - 30 | 9 | 25% |
| 31 - 40 | 11 | 31% |
| 41 - 50 | 12 | 33% |
| 51 - 60 | 2 | 6% |
| **Sex** | | |
| Female urban | 9 | 25% |
| Male urban | 8 | 22% |
| Female rural | 7 | 19% |
| Male rural | 12 | 33% |
| **Educational level** | | |
| No education | 10 | 28% |
| Primary | 13 | 36% |
| Secondary | 12 | 33% |
| University | 1 | 3% |
| **Diagnosis** | | |
| Schizophrenia | 35 | 97% |
| Other | 1 | 3% |
| **Health care used** | | |
| Western | 33 | 92% |
| Traditional | 0 | 0 |
| Both | 3 | 8% |

Table 4: Demographic Profile of Recipients (continued)

| Characteristics | Number (N = 36) | Percentage |
|---|---|---|
| History of illness | | |
| Yes | 12 | 33% |
| No | 18 | 50% |
| Unknown | 6 | 13% |
| Duration of illness | | |
| 0 - 4 | 5 | 14% |
| 5 - 10 | 8 | 22% |
| 11 - 15 | 10 | 28% |
| 16 and over | 8 | 22% |
| Unknown | 5 | 14 |
| Readmission rate | | |
| Urban | 5 | 18% |
| Rural | 1 | 5% |
| Non-compliance | | |
| Urban | 13 | 76% |
| Rural | 5 | 26% |
| Work history | | |
| Urban | | |
| Worked before | 14 | 39% |
| Never worked | 3 | 8% |
| Rural | | |
| Worked before | 5 | 14% |
| Never worked | 14 | 39% |

## Description of the Groups

Two group interviews were done in an urban setting and two in a rural setting. The groups varied in composition and size. The group size ranged from four to six members. In groups with ill parents, children were the main caregivers. For the ones where the adult children were mentally ill, the parents and siblings were usually the care providers. The sex distribution amongst the groups was adequate to assess the sharing of responsibility in collective caregiving situations between males and females (see Table 5 below). The recipients of care consisted of two females from the urban groups A and B (n=2) and two males from the rural groups C and D (n=2). Their age range was between 35-50+ years and three had worked before. Literacy level was high with three of the mentally ill persons having been to school. One had actually attended high school.

Table 5: Sex Distribution of Caregivers in the Groups

| Group | Female | Male |
|---|---|---|
| A | 5 | 1 |
| B | 2 | 3 |
| C | 1 | 4 |
| D | 2 | 2 |

## Relationship of Group Members to the Ill Person

The relationships of group members and the ill persons were captured as shown below (see Figure 2) and an identification code number and fictitious names were used to identify each participant in the group. The first member in each group consented to the group interview and assisted in assembling the members.

Figure: 2 Family Group Members and Relationship to Ill Person

| Group A | | Fictitious Names |
|---|---|---|
| GA 1.1 | Eldest son | Shima |
| GA 1.2 | Daughter in law | Thato |
| GA 1.3 | First daughter | Mpho |
| GA 1.4 | Second daughter | Lolo |
| GA 1.5 | Third daughter | Tshidi |
| GA 1.6 | Mother (Mentally ill person) | Bame |
| Group B | | |
| GB 2.1 | Father | Tiro |
| GB 2.2 | Mother | Nene |
| GB 2.3 | First brother | Tefo |
| GB 2.4 | Second brother | Kitso |
| GB 2.5 | Ill person (female daughter) | Neo |
| Group C | | |
| GC 3.1 | Grandmother | Nkoko |
| GC 3.2 | First maternal uncle | Sello |
| GC 3.3 | Second maternal uncle | Papi |
| GC 3.4 | Cousin (male) | Kgosi |
| GC 3.5 | Ill person (male grandchild) | Sekai |
| Group D | | |
| GD 4.1 | First sister | Lebo |
| GD 4.2 | Second sister | Shale |
| GD 4.3 | First brother | Pitso |
| GD 4.4 | Second brother | Petso |

*Note that for group D the ill person was absent.

## The Consent Process

Consent to conduct the study was obtained at individual and institutional levels. Permission was obtained from the Committee on Human Subjects at the University of California, San Francisco in January, 1996 (CHR Approval # H6164-12264-01). In Botswana, permission was obtained from the Office of the President, the Ministry of health, Ministry of Local Government and Lands, and local hospitals with psychiatric clinics which were utilized as focal points to recruit informants. Permission from the Ministry of Health was granted in November, 1995 (Ref. MH.13/18 XIX (43) and from The Office of the President in December 1995 (OP 46/1 L (113). These letters were to be presented when the hospitals and the clinics were visited.

Informed consent from the participants was obtained at the time they were recruited into the study. Participants gave verbal consent as this was culturally proper and acceptable. Appointments for interviews were scheduled after a brief description of the study was given. Participants were informed of their right to withdraw from the study anytime they wished. Interviews were conducted mostly in Setswana (the language spoken in Botswana). However, the participants were told to be free to use both Setswana and English; whichever was more comfortable for them. Permission to conduct group interviews was obtained from the person considered the head of the household who was then asked to assist in assembling all those whom she/he considered shared in providing care. After the group was assembled, their permission to participate was further requested and they were informed that they did not have to participate if they did not wish to. The informants were asked for their permission to tape record the interviews. All the informants agreed to be tape recorded and some requested that I play the tape back so that they could listen to themselves.

## Data Collection Procedures

Data collection began after permission from the respective authorities had been granted. Some delays were anticipated because of the festive season most government officers were on vacation. Semi-structured interviews, group interviews, and field observations were the primary methods of data collection.

### Individual Interviews

Informants were recruited using the methods described above from the respective settings. The purpose of the study was explained and their permission sought. If the informant agreed to participate in the study an interview was scheduled at a time and place that was convenient for the informant. However, it became apparent early in data collection that scheduling of interviews did not work well. Some informants would miss appointments. This was not only time consuming, but costly because of unnecessary travel for failed interviews. Ultimately, I refrained from scheduling interviews by date and time and would just inform the potential participant that I will come this week or next week for an interview. This was found to be feasible because it allowed some flexibility. I also allowed myself more time between the interviews. This was not done at first and it became overwhelming. In some instances, I would go into the field prepared for an on the spot interview if the potential informant so desired.

An interview guide was used but it was not followed sequentially. The content of the interview protocol included areas such as the experiences of the caregiving situation, feelings about caregiving, caregiving activities, concerns, worries, and problems that the caregivers encountered, support systems, and factors that impact on them. The interviews lasted one hour to one and half hours. Setswana was used to conduct the interviews. However, informants were asked to use either Setswana or English; whichever they felt comfortable with. Only a few (n= 5) used both languages. I conducted the individual interviews myself and this allowed the necessary probing from an interviewer with skills in communication and professional knowledge in nursing. It also created consistency across settings.

### Group Interviews

Group interviews presented an opportunity to see interactions between the participants and to use this group interaction to enrich meanings (Morgan, 1988). They also allowed observation of the power relations, interpersonal dynamics, and gender relations. The same protocol for the individual interviews was used for the group interviews.

### Field Observations

Field observations mainly utilized participant observation method by accompanying nurses during home visits and extensive notes were taken on what was taking place, what the nurses were doing, such as their interactions, and the dynamics. Informal conversations also took place when explaining the study to the potential informants. This method assisted me to corroborate and verify data gathered in individual interviews. After each interview, notes were made on the interview about the context, impressions, interactions, and feelings. Sometimes I would tape record myself describing an interview.

### Audiotaping Interviews.

The informants were asked if interviews could be tape recorded and none objected to this. Audiotaping of interviews preserved data that the researcher might have missed while taking notes. They also served as a means of validating data. Audiotaping assisted me in minimizing recall which could have resulted in misinterpretations. It also gave me the opportunity to focus more on what the informant was saying.

## Methods of Data Analysis

Data analysis began with my first interview and field observations and continued throughout the whole period of data collection. Data were transcribed in the language used to conduct the interviews which was mostly Setswana. The transcription time was agonizingly slow. It took 8 hours or more to transcribe a 60 minute tape and almost two days to transcribe a 90 minute tape.

Data were analyzed in both Setswana and English. Initially I planned to analyze data in Setswana and use English when developing the categories. I found this difficult because some concepts were captured better in either English or Setswana. Therefore, I had to choose the language that could succinctly capture the meaning and the two languages were used concurrently. Opening coding was done word for word , line by line, paragraph by paragraph. Like data were grouped and re-grouped into sub-categories and major categories. The data were constantly compared and re-grouped together into major categories through a process of axial coding.

## Methodological Issues in Qualitative Research

### Ensuring of Rigor in Grounded Theory

Several methods and guidelines have been provided for judging the adequacy of naturalistic inquiry or qualitative research. Guba and Lincoln (1989) stated their criteria as credibility, applicability, or fittingness, and auditability. These criteria resemble internal and external validity, reliability and objectivity in positivistic paradigm (Kirk & Miller, 1986). Sandelowski (1986) reviewed Lincoln and Guba's criteria and affirmed their usefulness for qualitative nursing research. Janesick (1994) also outlined five strategies that can be used to enhance rigor in qualitative research. These include: adequacy, appropriateness of the data, audit trail, verification of the study with secondary informants, and multiple raters. Data adequacy refers to the amount of data collected rather than the number of subjects in the study. Adequacy is attained when sufficient data have been collected and saturation occurs and when variation is both accounted for and understood.

Appropriateness refers to the selection of information according to the theoretical needs of the study and the emerging model. Sampling is done purposefully until repetition from the multiple sources is obtained. This confirms the data, thus ensuring saturation. Consequently, the results of the study are enriched and can be construed as more valid (Morse, 1986). An audit trail refers to adequate evidence through which interested parties could reconstruct the processes and procedures by which the investigators reached their conclusions (Janesick, 1994). To saturate data, theoretical sampling had to be done and when no new data were forthcoming, the researcher knew that the category had been saturated.

Verification of the study with secondary informants confirms the accuracy and the validity of the study. This may even offer additional data to confirm, refute or amend the model (Glaser, 1978). I verified data by recording and checking and rechecking by listening to the tapes and comparing data with field notes. Verification or confirmation was also achieved by probing and seeking clarification during interviews. This was done in order to avoid misinterpretations and misrepresentations. Verification was also achieved by checking the findings with other people. Interviews were read to some informants and they were asked to make comments on the accuracy of the reported thoughts and to say whether they could identify or relate to some of the experiences expressed. Some colleagues in the Department of Nursing Education at the University Botswana and mental health nurses practicing in the area were also given some transcripts to read and to see if they could relate to some of the reported experiences.

The credibility and fittingness of my findings were tested by informally presenting themes and analyses to the informants as the data collection proceeded. Themes and concepts were also be presented to fellow colleagues in the field and in other fields such as the linguistics department to seek their feedback concerning the fit of my analytical explanations to their daily experiences.

Auditability was demonstrated by regularly presenting emerging themes with supporting data in the research. Auditability is also crucial in the final reporting of the data, as the decision trail should be clear in the results section. All procedures for data collection and analysis have been documented in order for the reader to audit what happened and how (Kirk & Miller, 1986). Strauss and Corbin (1990b) judge the results of grounded theory by determining if concepts have been generated and concepts are systematically related, if the results have explanatory power and show variation and process or if the findings seem theoretically significant. Relationships were sought and connected and variations were also noted.

Validity of qualitative research can also be enhanced by triangulation. Triangulation is defined as a combination of multiple methods, perspectives, and observers in a single study (Denzin, 1989; Denzin & Lincoln, 1994; Mitchell, 1986). The authors identified five basic types of triangulation: data source, investigator, theoretical, methodological, and interdisciplinary.

Data sources were triangulated in order to obtain data from the various members of the family caregiving group which further clarified and elaborated the examination of multiple caregiving situations in Botswana. The data sources utilized in this study were individual and group interviews of family members and others who shared in the caregiving situation, and investigator observations, including non-verbal communication and field observations. Group interviews were particularly appropriate in this situation because several people and their interactions allowed multiple perspectives to be expressed. The group interview method facilitated observation of the interaction and dynamics of the caregiving situation more broadly; for example, power relations and dominant informants in the situation indicated who made the final decisions about the care.

## Reflexivity

One of the methodological concerns that frequently emerge when conducting research is the degree to which the investigator can be personally involved in the research process and still retain some measure of objectivity (Lamb & Huttlinger, 1989). During the course of the research, a kind of critical thinking takes place that reflects on the dynamic interaction between the investigator and the total research environment. This is referred to as reflexivity and is a process in which an investigator seeks to understand how her personal feelings and experiences may influence the study and then strives to integrate this understanding into the study (Marcus & Fischer, 1986). Reflexivity requires the investigator's self awareness and considers possible influence of the researcher's personal characteristics on the study. These characteristics include personal beliefs, values, interests, race or ethnicity, gender, class and other demographic issues. According to Lincoln and Guba (1985) reflexivity is incorporated into the research method in order to offset investigator bias. The authors contend that undue researcher bias is considered to be a threat to the credibility and confirmability of qualitative research. The researcher in qualitative research is considered a data collection instrument and, thus, the reliability of an instrument to measure accurately requires reflexivity (Wilson, 1985).

Lipson (1991) has espoused the effective use of self in qualitative research. Lipson argues that "researchers in grounded theory approach use themselves as both data elicitors and processors who do ongoing analysis for the purpose of generating categories for theory construction" (1991, pp. 74). Therefore, constant conscious reflection on oneself is vital in research, particularly qualitative research. The effective use of self is considered in the development of rapport and in the gathering and processing of information (May, 1989). Lipson (1991) argues that an interview is an interpersonal encounter, it is vastly improved by mutual understanding, rapport, and trust.

Another point involves controlling emotional responses which is not only difficult but exhausting, especially when conducting interviews about a sensitive topic. Questions are raised as to how attempts to control feelings may be perceived and what effects these may have on the informants (Lipson, 1991). Lipson asked if it is better to control strong feelings or to more openly acknowledge them and try to explain one's reactions. There are no cut and dried answers to these issues because each situation in which the researcher finds herself or himself is different.

When a researcher is unable to be reflexive, potential biases of the research are glossed over and hidden. Reflexivity was achieved by always stepping back and reflecting on myself in order to avoid misinterpretation and misrepresentation of the research findings. A journal about my feelings, frustrations, satisfactions, and dislikes in the research process assisted me in maintaining reflexive and critical thinking.

There were many frustrations in conducting this research. It was very sad to uncover the difficulties and agonies that the families were going through. Some of the families did not have anything to eat and it was ironic to expect these ill persons to comply with treatment. Although I knew my role as a researcher, assisting the families was inevitable. I helped some families to register for food rations. One of the things I found frustrating was that the criteria for food rations were unclear. Officers responsible for the food programs used their own discretion about who to register for food rations and excluded some very needy persons. At times I brought food for the family from my own home, but this would really not take them a long way.

Memo writing during this period was very helpful. Memos were sometimes safety valves to ventilate feelings and to process analytical thoughts. If the interview was a sad one I wrote a memo about it and expressed my feelings. I also kept a diary to reflect on as I went through the research process. As an investigator, I realized that I was undergoing some change and development. My skills in conducting qualitative research got more refined and I developed more confidence.

I contemplated abandoning this project on several occasions, but talking to some colleagues about my feelings sustained me throughout the painful and sad data collection phase. I observed cautiously so not to impose my ideas on the informants by doing less talking to allow them to relate their painful experiences. I always felt a lot of empathy for the families but also admired their courage and strengths. This admiration served as an incentive to want to know and learn more about these families and their situations in order to assist them.

## Ethical Considerations

Nursing research by its nature requires that many ethical considerations be addressed. The ethical issues most commonly mentioned in qualitative research include informed consent; deception or covert research; the researcher's responsibility to informants, sponsors, colleagues; risks versus benefits; and, to a lesser extent, reciprocity and intervention (Lipson, 1993). Health researchers are bound by a professional code of ethics. Davis and Aroskar (1991) contend that the ultimate dictum for health researchers is "nonmaleficence" which means "to do no harm." Another closely associated ethical principle to "nonmaleficence" is "beneficence" which means "to do good" (Davis & Aroskar, 1991, pp. 45-46).

Conducting this clinical research presented a challenge because certain ethical issues and the realities of life had to be transcended, such as whether or not to intervene in a research setting. This was a dilemma because if I did not intervene it would still be ethically equated to doing harm to the families because I had information about how I could assist the families in partially solving some of their problems. As mentioned earlier, interventions were done after data had been collected. I considered it ethical to intervene, but I did so after the interview to prevent changes in responses because of my interventions. Most of the situations were so compelling that one had to be inhuman to leave without any intervention. On the other hand, had I not intervened, the principles of "nonmaleficence and "beneficence" would have been violated. Therefore, in clinical research if intervention is considered unethical, lack of it could even be more unethical.

The other issue that presented a problem for me ethically concerned the recruitment of informants. The initial plan designed for their recruitment did not seem to work very well. Initially the informants were to be identified through their mentally ill relatives when they came for check ups. However, in most instances they would forget to inform their family members about the study. The mentally ill went for check ups only once a month. The recruitment process was slow and made me very anxious. Therefore, I decided to ask the local clinic staff for assistance in the identification of potential informants. Asking the health staff to accompany me to the families' homes seemed like they were being coerced because they could not disappoint the nurses who assisted them in the care of their ill relatives. This was not an ideal alternative but it was found to be feasible.

The principles of "nonmaleficence" and beneficence" are clear and easy to understand, the risk of their violation is great, especially in qualitative research because of its unpredictable nature. It was impossible for me as the researcher to totally predetermine the course the research would take but I had to be as cautious as possible to seek the informants' permission and to constantly inform them about their rights to withdraw if they so wished. Informed consent was sought all the time and participants were alerted that of the possibility of my coming back again to talk to them to validate or clarify some issues if need be.

Ramos (1989) argues that the inherent unpredictability of qualitative research undermines the spirit of informed consent and endangers the assurance of confidentiality. The researcher was always mindful to ensure protection to the informants especially their confidentiality. Code numbers were assigned to them so that data could not be traced to them. The participants were also informed of what was going on in this study. Another ethical issue that confronted me and still does is how to use these data to bring about change for the family caregivers so that their 'voices' could be heard so that they made an impact on the authorities without violating the informants' confidentiality and privacy.

## Issues of Translation

Translation is another problem that can threaten the validity of qualitative research. The goal of translation is to assure loyalty of meaning and equal familiarity and coloquialness in each language. Translation should achieve cultural equivalence which takes into consideration both denotative and connotative meanings (Marin & Marin, 1991). Differences exist in the connotation of certain words, phrases, and metaphors in many languages. In Botswana, the use of proverbs and metaphors is common and these can be difficult to translate into English without the meaning being lost completely. As with many languages, Setswana has many vocabulary variations and these were taken into consideration.

Various procedures are often employed in research to overcome problems of translation, such as hiring bilingual persons to perform the translation or if the researcher is bilingual, he/she may often translate data (Werner & Campbell, 1970). A consultant from the linguistic department was engaged to translate the interview guide into Setswana and back into English to avoid loss of meaning. Colleagues in nursing were also utilized to assist in the interpretation of some data to determine if agreement existed. Some transcripts were also read to the informant to see if they identified with and related to them.

Translation of qualitative transcripts can be problematic because eventually it is not clear to whom the transcripts really "belong", because they are not exactly what the respondents said (Fine, 1993b). Nonetheless, the researcher in the final analysis will find ways of how to ensure validity of the findings in order to avoid inaccurate representation of the respondents.

Translation problems were overcome in this study by conducting the interviews in Setswana. It was noted in the pilot study conducted (Seloilwe, 1995) that some rich meanings in the data were completely lost when transcripts were translated into English. In order to minimize problems of misinterpretation and misrepresentations, translation of data into English was not done until analysis had been completed so that the actual meanings of the data could be captured and retained. However, this process was found to be overwhelming and time consuming and was abandoned. It was feasible only to translate the excerpts that were going to be used as quotations. Some of these translated excerpts were shared with colleagues to be constantly checked so that meaning was not lost.

Issues related to translating transcripts in qualitative research have not received adequate attention in the literature. Having undertaken a qualitative study in a different language and translating it into another I have a heightened sense of the need for further examination of this issue. There are arguments that transcripts should be translated verbatim. This notion seems to work only if transcription is done in the same language that was used to conduct the interviews. However, translating those transcripts verbatim does not necessarily work well because some ideas do not make sense if translated verbatim. According to my opinion, translation in qualitative research should be done to capture meaning and should not be done verbatim. This also raises the question of to whom, then, will the data "belong" after this kind of translation? These issues remain to be resolved the best way we know how. For example, one of the strategies that the families reported they use to cope with caregiving situation was "*boitshwaro*." This term is difficult to translate. Specifically it may mean self control, self discipline, control of one's feelings and actions. But deeply it encompasses the total human behavior of just how one conducts herself/himself in the caregiving situation.

Another example is somebody saying *"ke segole same."* Verbatim translation would be "he is my crippled or disabled person." This totally distorts the meaning and it does not make any sense. What is meant by this expression is that the caregiver is accepting the ill person as he/she is, and expressing feelings of acceptance or willingness to live with the situation. This expression is also not made in a negative manner.

The translation therefore, is delicate and can be a frustrating activity that is often flawed with inaccuracies, blurring the original meaning and picture. The central concern of translation in qualitative research is the lack of equivalent meanings between two languages. Every language has both connotative and denotative meanings and to find words that explicitly express connotative meaning between two languages can be a problem because the meaning of words are culturally derived. Batswana commonly express themselves by use of metaphors, proverbs, and idioms to enrich and embellish their discussions. Translating metaphors, proverbs and idioms is not only problematic but very difficult. The result is loss of rich data descriptions which are attenuated by translation.

## The Permission Process

Although I returned to Botswana in November 1995, data collection did not commence until mid February 1996. This was because permission to conduct this study had to be requested again in Botswana. The process was very rigorous in that the documents went through many bodies at multiple levels. The first level was the Office of President, then the Ministries which were directly affected by the study, in this case Ministries of Health and Local Government, Lands, and Housing and their departments and local clinics.

Although the University of California San Francisco institutional review board (CHR) granted me provisional approval early January 1996, I could not start interviews until CHR received letters of approval from Botswana. The final approval was granted on the 19th January 1996. Although this process is very necessary in human research, it nonetheless caused delays in the commencement of this project.

### Recruitment of Informants

As already mentioned, this was another area that was problematic for me. The initial plan to recruit informants was abandoned for the reasons already alluded to. Missed appointments were also problematic. However, I employed alternative measures to address the problems. I refrained from scheduling interviews by date and time. I designated days that were mainly for recruiting informants and days for interviews. When informants were recruited and they agreed to participate, they would be informed that an interview will be done that week or the following week. This was found to work much better and it seemed a more culturally appropriate strategy.

Assembling of family groups was also difficult because it took too long for family members to come together especially those who did not reside with mentally ill person and yet made decisions about the care. Problems on assembling a group were more difficult in the urban than rural settings. This could be attributed to the fact that family members in the urban sample were employed while those in rural were not. Some participants in the group discussion dominated discussion more than others especially heads of families.

### Seasonal Migration

Seasonal migration was another factor that impacted the progress of the study. During the months of November to August people migrate to the lands to plough and they stay there until their crops are harvested. Data collection had to start in Gaborone and finished in July 1996. Data collection in Molepolole did not start until September because most people were still working in their fields. There were good rains that year and harvesting was delayed.

### Performing Interventions

Time management was a very important factor in conducting this research. The data indicated many problems for which families needed some intervention. As a clinician, I felt obliged to assist the families to access available resources. Often these simple problems took a very long time to solve. I saw myself as the hope for these families. However, interventions took away time from the study.

### Lack of Resources

Lack of adequate funding restricted the settings of the study. Caregivers in other areas need to be accessed and their situations be understood. Populations in Gaborone and around have greatly benefited from research because their problems have been examined and this may result in their problems being appropriately addressed.

# CHAPTER FOUR: THE FAMILY CAREGIVING SITUATION

## The Tswana Family

This study investigated family caregiving situations of the mentally ill in Botswana. It should be noted that most families in this sample were extended in nature. Although individual in-depth interviews focused on one member of the family as the key informant, this person was not the sole provider of care. There were other family members who helped and shared in the provision of care. Therefore, the caregiving situation was a collective endeavor with all members of the family cooperatively sharing the responsibilities of caregiving.

Due to the complex nature of the family in Tswana culture, it was imperative to develop a conceptualization of the term family from the perspective of the caregivers themselves. This conceptualization of a family was developed by asking the participants in this study to define what they understood a family to mean to them. There was a lot of variability in the usage of the term family because of the different forms, types, and composition of the families. Moore (1994) noted that the concept of family is influenced by contextual factors that include but are not limited to customs, norms, and expectations, laws, politics, and economic relationships . She further noted that the concept of family may not be stagnant and consistent, but keeps on changing. These changes are influenced by several factors such as demographic trends and industrialization e.g., as countries industrialize, a substantial rise in the number of cohabiting couples and single person households has been observed.

According to Fako (1979), traditionally, a Tswana family consisted of a man, his wife or wives, and their unmarried children, own or adopted. According to Setswana culture, an adoption did not involve any signing of documents. It was a verbal agreement between the two families. Very often people adopted children of their relatives and it was very uncommon to adopt children from strange families.

Families in this study were asked to define a family *(Lwapa or Lelwapa)* and many different definitions were advanced. It is worth noting that people's definition of the family may be influenced by several factors such as their level of education, socio-economic status, and cultural orientation. Some saw the family as consisting of a man, his wife, and children. If grandchildren were included, then the family was considered extended.

> CG005: According to me a family is myself, my wife and children but if I include my grandchildren then my family will be extended.

Some caregivers saw a family as more than just a man, his wife and children. They saw a family as encompassing their parents as well as their siblings. They further stated that members of the family may be spread across several households and households may contain individuals who were not part of the unit comprising of the conjugal couple and their children. Members of the family were considered not necessarily co-resident and co-operating.

> CG004: My family is my wife, children, grandchildren, my parents, my siblings, and those closely associated to me. Your family are people you cooperatively associate with (*batho ba o dirisanyang le bone)* .

According to this perspective, family members may include those people with whom one has close relationships and associations and they may not necessarily be related by blood. In this sample, there were family members who shared in the caregiving responsibilities who were not related by blood to the ill persons.

The assertion that family members may not necessarily cooperate was demonstrated by the fact that one member of the family would sacrifice and assume the caregiving roles when others are less concerned. Also, some members of the family who made major decisions did not necessarily live with the mentally ill person.

Almost all the families included in this study except for two were extended. It was observed that these families had strong intimate relationships, obligations, expectations and shared in many ways. Sharing of meager resources was the main central force in these families. This was evidenced by one or more members of the family working and financially supporting the rest of the family members. However, the resources were always inadequate to meet the needs of the family because of many dependents. The following are some genograms to illustrate the constitution of the families that were studied.

Legend for Genograms:

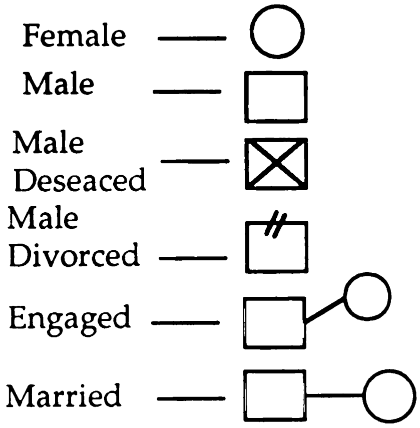
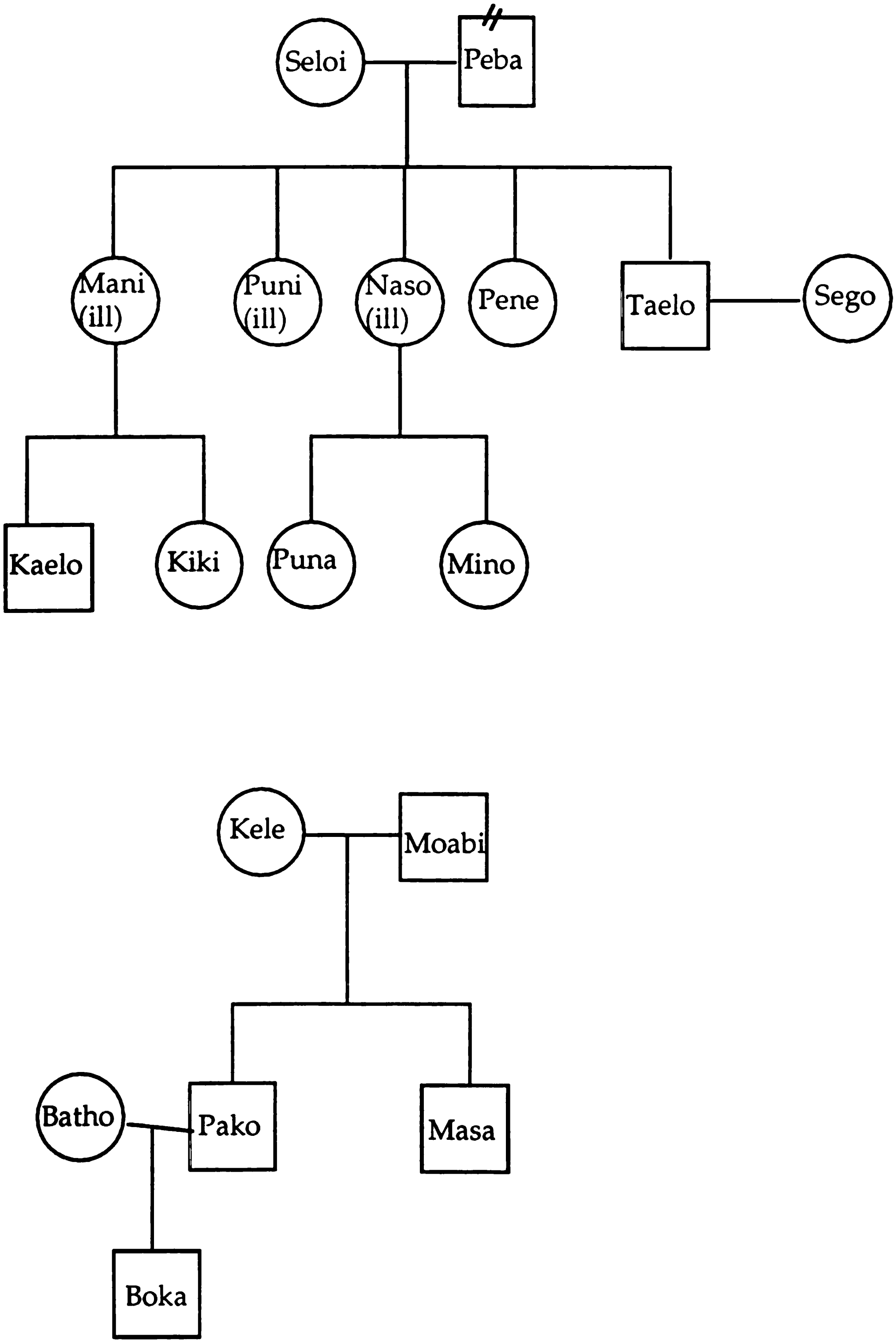
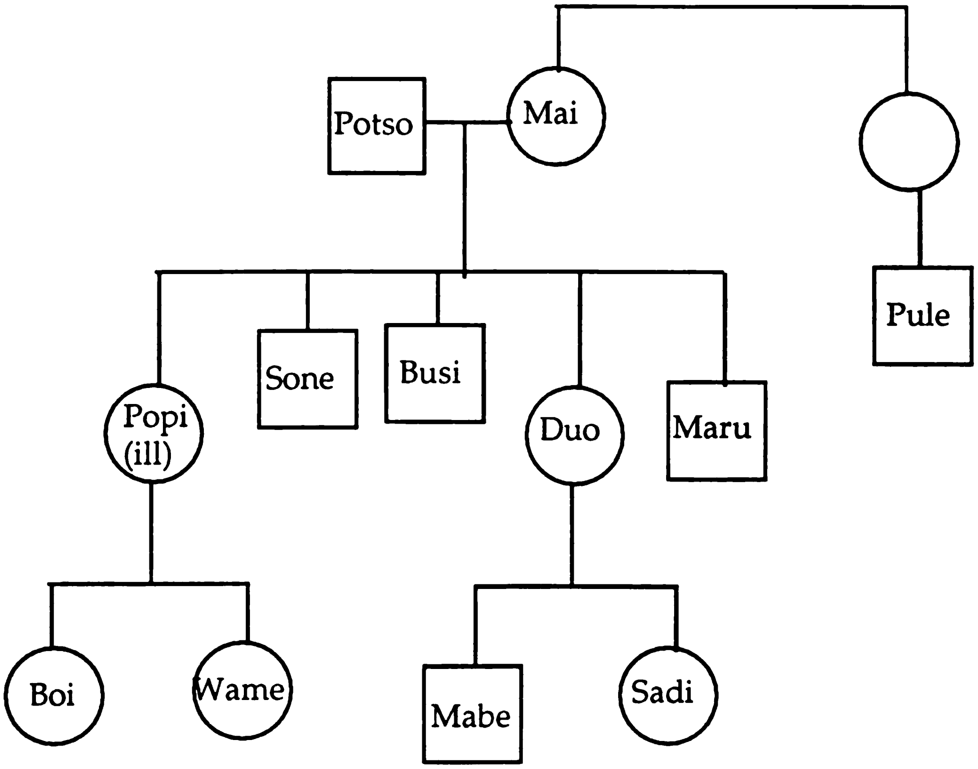
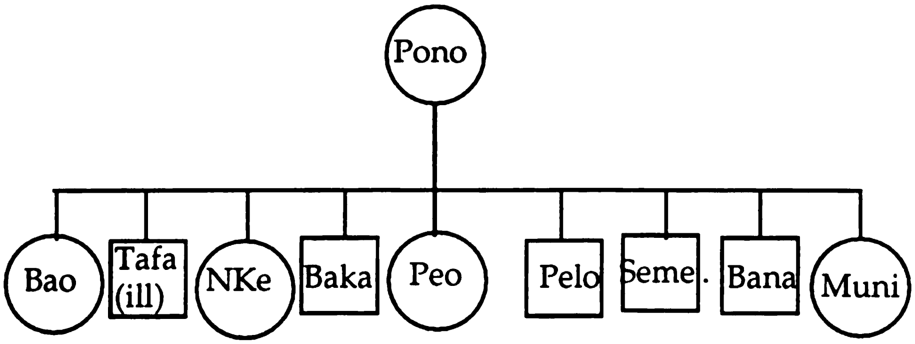


Figure: 3.1 Genograms of a Few Selected Families in the Study



Family Genograms (continued)

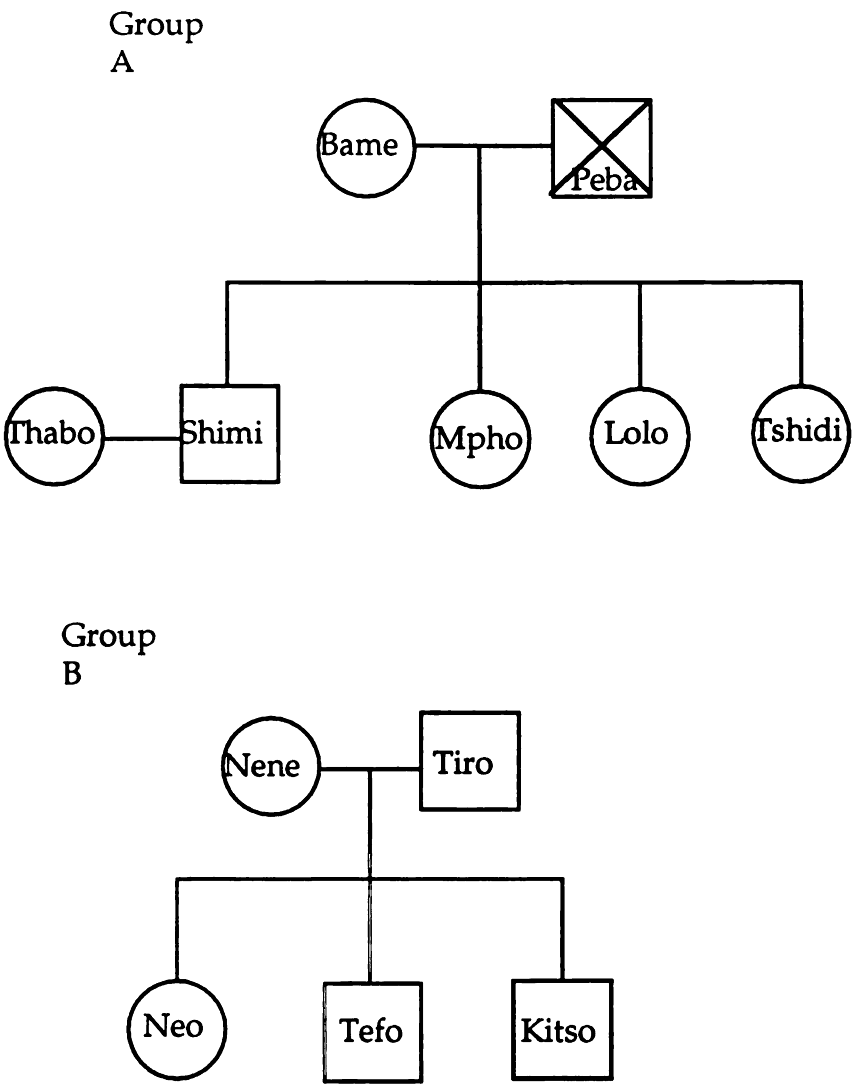




## Presentation of Family Group Interviews

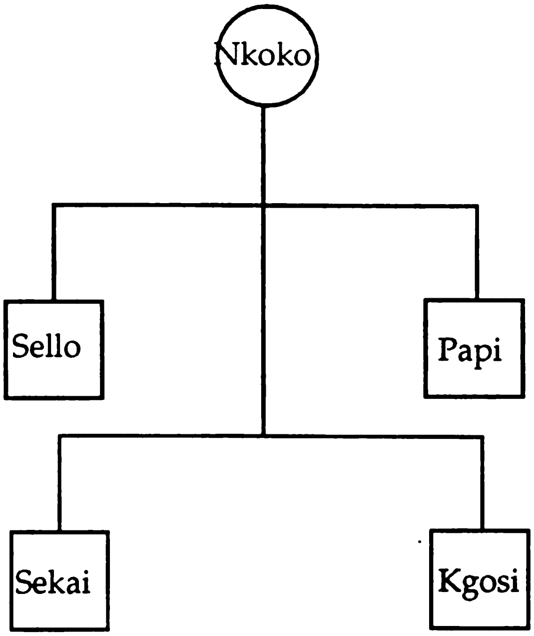
Family group interviews were specifically used to understand the concept of multiple caregiving. It was believed that, in a group discussion the nature of how responsibilities were shared came out clearly through interactions and relationships . The purpose of family group interviews was also to explore these collective caregiving situations to elicit information on how families cooperatively undertook caregiving responsibilities. The group interviews are presented in case study form and collective caregiving properties will be drawn for further discussion. All the four groups are presented because each presents uniqueness in understandings, relationships, and interactions. The group compositions in the form of genograms are as follows:

Figure: 3.2 Group Composition

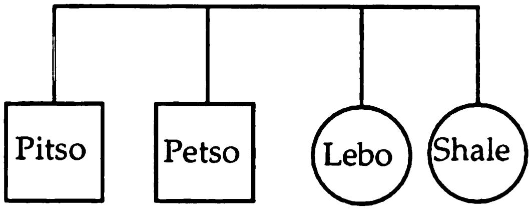


## Group Composition (continued)

Group
C



Group
D



## Group A

Introduction. I got to the gate and it was locked and I called out for somebody to let me in. The family members were seated in room and seemed ready for the discussion. We exchanged greetings to break the ice and establish some rapport. The brother Shimi who was symbolically taken as the father figure introduced me to rest of the family. I explained the purpose of the study and interview to the family members and asked for their permission to participate in the interview. I also informed them that they were free to withdraw anytime they wished and that I wished to audio tape the discussions. All family members gave verbal consent to participate in the group interview.

Setting. The group was conducted in White City in Gaborone, which is a low income area. The housing was adequate. The house had three bedrooms, living room, kitchen, indoor bathroom and toilet and had running water in the house. Six members of the family lived here and they included the ill person, two daughters and three grandchildren.

Composition. The group was composed of six members. The ill person who was their mother Mme Bame, her son Shimi, daughter-in-law Thato, and her three daughters Mpho, Lolo, and Tshidi. Shimi, Thato, and Tshidi did not live in this household. The grandchildren were not included in the discussion. Mpho, one of the two daughters who lived with Mme Bame, was the key caregiver because she was responsible for the day to day care. The rest of the ill person's children had full-time employment. The family stated that they decided that Mpho who was not employed should be responsible for their mother's care and those who were working provided material and financial assistance. They mentioned that this was a consensual agreement. Although Shimi was the main decision maker, they were always consulted on Mme Bame's care. When there was a problem, Mpho contacted her siblings and notified them of the problem. This was mainly when they felt their mother needed hospitalization or further medical consultation. Lolo often helped with providing some relief for Mpho especially during weekends. They mentioned that their mother would not agree to go and live anywhere else except in her own home and they felt it was good for her to be at home. The members of the family who lived with the ill person shared in the performance of household chores. The family members stated that they encouraged one another to be open and honest about their feelings and to express their differences freely in order to resolve their problems because otherwise their mother would be the one to suffer. They mentioned that Shimi was very supportive of them and really wanted them to pull together especially after their father's death *(ba nne seoposengwe).*

Impressions. This family exemplified sharing of responsibilities by sharing different aspects of care. They worked as a team and pulled together. Bame's illness seemed to have brought them together. They consulted in making decisions about the care. They cooperated and showed cohesiveness. They provided for others in the family who did not have the means. They also provided some relief for Mpho who took care of their mother on day to day basis. They showed respect for one another, especially their brother whom they regarded as their symbolic father.

## Group B

Introduction. We entered the yard and exchanged greetings with the members of the family. Then Rre Tiro introduced me to his family. I introduced my assistant and said that he would be involved mainly with recording. I explained the study to the family members and informed them hat they were not forced to participate if they did not want to and that I would like to audio tape the interview. The members gave their verbal permission to take part in the interview.

Setting. The interview took place in the Broadhurst SHHA extension 16. This is a low income area. The compound consisted of a two room house for the family and adjacent to it was a four room building. All these rooms were for rental. The houses were not plastered, did not have running water, no kitchen, and no bathroom. There was a cooking area *(leiso)* and a toilet outside. The stand pipe (communal water source) was about 40 meters away. At one end corner of the yard was a small kiosk selling small grocery items *(Semausu).* Six people lived in these two room house.

Composition. The group was composed of the father Rre Tiro who was the head of the family, the mother Mme Nene, the ill daughter Neo, and two brothers Tefo and Kitso. Mme Nene was responsible for the day to day care of her daughter Neo and did all household chores with the help of Neo when she was okay and her grandchildren Oteng and Kabelo when they were out of school. Rre Tiro also assisted with management of the daughter's care especially if she was not taking her medications well and also in resolving conflicts within the family members. Rre Tiro, Tefo, and Kitso mainly helped with finances and provision of material goods that the family needed. Rre Tiro dominated the discussion and everybody looked to him to speak on their behalf. Mme Nene would seem to seek his approval by looking at him before responding to a question. Tefo and Kitso were quiet during the interview and only responded if the question was directed specifically to them. They mentioned that they assisted in the care of their sister Neo by providing financial assistance and checking on their family to see how they were doing *(Ba ba lekola).* Tefo and Kitso stated that they visited their family about two to three times a week. Rre Tiro said that they were trying everything to help

Neo to become independent and work for her children because she used to be a hard worker. He expressed the need for craft schools and some kind of education that could assist mentally ill persons to find employment because education or possession of some skills were the only things that could enable them to live a better life. Neo also commented and said her parents did not really understand her illness. There were days when she did not have energy and did not feel like doing anything and they always thought she was lazy (she was becoming emotional as she said this). Rre Tiro interrupted and asked Neo to stop talking and she did.

Rre Tiro, who was the head of the family, made decisions about Neo's hospitalizations and who to consult, a traditional healer or western one. He really seemed to be in control of the situation. He mentioned that his resources have been depleted by Neo's illness. He had sold all his cattle to pay the traditional healers but still Neo had not improved. He expressed his dissatisfaction with the nurses because they never visited them and he would like to see mentally ill people being taken good care of by the government.

Impressions. In this interview Rre Tiro was dominant and it was evident that he was the one who was in control as the head of the family. There was sharing of responsibilities. However, Mme Nene ran the household while others assisted with material resources. Tefo and Kitso also supported their parents emotionally by visiting them and checking on them.

### Group C

Introduction. It was a very nice sunny morning and the family had assembled outside. We got in and sat down and exchanged greetings with members of the family. I informed the group about the purpose of the study and requested their consent to participate. The group members agreed to participate and were informed of their right to withdraw anytime from the group. They were also asked if the interview could be audio taped and they showed no objection.

Setting. The interview took place in Borakalalo ward in Molepolole. The household was composed of two thatched huts and a three room iron roofed house. The house had no running water, no kitchen, but there was a cooking place outside. At the back of the houses was a pit latrine. The stand pipe was about 50 meters away.

Composition. The group was composed of five members; Nkoko, Malome Sello and Papi (maternal uncles), the ill person Sekai (grandson and mentally ill), and his cousin Kgosi. Nkoko was the one who took care of her grandson on a day to day to basis. Malome Sello lived nearby with his family but assisted Nkoko with the care of his nephew Sekai. Nkoko started by giving a brief description of how the illness started, that her grandson Sekai started acting in a funny way soon after his mother died and they thought he was troubled by ancestral spirits (*A tsamaiwa ke Badimo).* They performed some rituals to appease the spirits but to no avail. Sekai was then taken to the local hospital (Scottish Livingstone hospital) where he was transferred to Lobatse (Mental hospital). Ever since then Sekai's illness has been on and off. Sello stated that his nephew Sekai had never really been mentally disturbed, the problem with him was that he drank too much beer and smoked *dagga.* He explained that he was the only one who had reached the highest level of education in their family and they looked upon him to help Nkoko. Sekai held many jobs but did not value them because of his drinking problem. He felt that if Sekai could stop his drinking things would be okay. A complaint was raised that Sekai did not show any respect for anybody and would not take advice from them because they were not educated. He expected Nkoko to cook and do laundry for him. When he got up in the morning he took off to the village and when he returned he expected to find food, otherwise he would harass his grandmother. Sello stated that he has tried in vain to assist Sekai to get employed and when he was given money to go for job interviews he drank beer with it. Sekai interjected and said that all that was being said about him was not true. It was mentioned that Sekai was not cooperative and when he was asked to do something by his uncles he expected them to pay him, but he wanted and expected them (his uncles) to do things for him e.g., support him financially. His uncle Sello said that he provided them with material goods occasionally and it was becoming hard and difficult for him.

Nkoko expressed concern about Sekai because she did not know what his future was going to be, especially if she goes (meaning when she dies). She was concerned because her grandson Sekai was quite capable of working but he would not just find a job. She has talked to him and tried to show him that his uncles were only doing what they could do because of her but the moment she goes they would not anything for him. While the group was still on Sekai left. They said "you see this is what we are talking about, he does not have any respect for anybody." Asked if he was taking his medicines they said he wasn't. Asked what they were doing about it, they said they were going to report to the nurses that he refused to take his medicines but they had not found time to do that. Nkoko said she had not been well herself so she could not go the hospital to report.

Impressions. This was a very complex and sad situation. The family did not seem to understand the magnitude of the problem. There were a lot of complex dynamics within the group because the discussion centered around complaints about Sekai's behavior. A great sense of despair, helplessness, and hopelessness about the situation was shown. The family seemed to have a lot of conflict over Sekai. Nkoko seemed to be the major link in the relationships and the assistance that Sekai received was because of his grandmother. As the Nkoko clearly pointed out, his uncles Sello and Papi would not assist him when she is gone. The relationships have been strained and there were signs of giving up. There was lack of reciprocity on the part of Sekai. This group revealed that extended networks did not always guarantee support. Sekai's condescending attitude will make him lose support from his uncles.

### Group D

Introduction. We exchanged greetings like in other groups and introductions were done. The study was explained to the participants and their consent was sought and they were informed of their rights to withdraw if they wished. Their permission to audio tape the discussions was sought. Participants gave verbal consent.

Setting. The interview took place in Bokalaka ward in Molepolole. The household was composed of one thatched hut and two iron roofed houses. One had two rooms and the other one had four rooms that were still under construction. The surroundings were clean with a nicely decorated patio (*lelwapa*) and there was some sorghum malt (*momela*) spread to dry in a scorching summer sun getting it ready for brewing Tswana traditional beer.

Composition. The group was composed of two sisters Lebo and Shale and two brothers Pitso and Petso. The eldest sister Lebo was the one who was the main caregiver. The family members stated that they shared in their ill brother's care. Lebo and their mother were the main people in his care. Lebo took care of him when he was in the village and their mother took care of him when he was at the lands. They preferred their ill brother to stay at the lands because the environment was good because there was no beer there unlike in the village where there was a lot beer brewing. They said that their ill brother's condition was exacerbated by beer and he would go into people's shops and take goods without paying and these people usually called the police on him. This made them very sad because they knew he did this because he was sick. This behavior had strained relationships with the shop owners in the neighborhood because very often the family members would not have money to pay for the goods so as to resolve the situation amicably.

It was also difficult to confine their ill brother to one place. The other reason why they wanted him to be at the lands was that he functioned better there because he herded cattle and did anything that could be done by any "normal" person. The family members expressed feelings of sadness and sorrow when they spoke about their ill brother because they said he used to provide for all of them and he took good care of himself *(A le seithati).* They expressed feelings of inadequacy in trying to measure up to his level and this made them feel unable to care for him. They helped one another and cooperated in his care by sharing responsibilities. Lebo and Shale mainly did household chores while Pitso and Petso helped with more strenuous task such as gathering of fire wood and water using drums. They also provided financial and material assistance. However, Pitso and Petso performed household chores if Lebo and Shale were not there or were held up. Pitso and Petso also remained with their ill brother and kept him company to occupy and prevent him from wandering around in the village. A conflict of interest was observed because much as they did not want their brother to drink beer, Lebo brewed and sold traditional beer in their home to earn a leaving. This was one reason why they preferred their ill brother to live at the lands, although their ill brother shuttled between the village and the lands.

Impressions. This family cooperated and shared responsibilities in the care of their ill relative. They felt inadequate in providing care but maximized their resources. They offered each other respite care by alternating in providing care for their relative. They also seemed to be pulling together and working like a team. However, a conflict of interest was observed in their desires and actions as already mentioned.

## Multiple Caregiving

Multiple caregiving refers to the family members acting together and cooperatively by sharing the responsibilities of caregiving. The group interviews above were used to illustrate how the family members cooperated, collaborated, and shared responsibilities of caregiving. Multiple caregiving situations had several people providing care and several people receiving care. Also, some families had more than one mentally ill person. Thus the caregiving situation was very complex in these situations.

### Sharing of Responsibilities

The caregivers reported that sharing of responsibilities was a collective endeavor in the home. The investigation looked at who did what , under what conditions. Designation of responsibility to provide care took two distinctive dimensions. The key caregiver either voluntarily assumed the responsibility or it was assigned by other members of the family after due consultation. The assignment of caregiving responsibilities looked at several factors such as if that member of the family was not working and thus other members of the family who worked would support the caregiver and the ill person. These were the conditions that also made her the key caregiver. Consultation in making these assignments was mostly apparent where a parent was the ill person. Collective caregiving situation also included multiple recipients of care These included not only the ill persons, but the caregivers themselves, and other dependent children.

> CG008: We talked about who should take care of my mother. This was after my father died. He was the one who always took care of her because we were still young. My brother and sisters thought that I should be the one to do it because I was not working at that time. I had left my work because my husband died and I was still wearing that black dress. I did not want to go to work in black dress. I hated it. So I was still waiting at home for a year to pass and then I could look for a job. Then my father died and then I had to take care of my mother.

In a situation where the assignment of responsibility for care was done cooperatively, the family functioned like a team and consulted one another when there was a major decision to be made. The onsite caregiver contacted others to meet and discuss how to resolve the problem.

> CG008: When there is a problem if she has to go to the hospital I call them and we talk about what has to be done because I cannot decide certain things alone. My eldest brother is the one who decides because we just take him like our father now. But all of us decide what to do.

> CG007: When things have changed I notify my eldest sister and she comes over to decide what we can do. She doesn't live with us but she comes when we need her.

Consultations about what decisions to make were mostly evident where a parent was the ill person. This could be attributed to the fact in these circumstances, not anyone has absolute power in the care of a parent. The children act cooperatively and consulted on the care (see group A).

The group family interviews also showed that the family members cooperated, collaborated, and shared responsibilities of caregiving. However, where both females and males were involved in the care, the former did most of the household chores whilst the latter did work that was considered to be more demanding or too difficult such as collection of firewood or drawing of water using drums. The males performed household chores when their female counterparts were not there or were preoccupied or held up by something. This was demonstrated in group D. Most males in the caregiving situation saw their contribution in the care as providing resources like financial and material support. This was vividly illustrated in the family group interviews. The group interviews also showed that caregiving responsibilities were considered the prerogative of women. In all four groups, women handled the day to day caregiving responsibilities. The role of the males was mainly that of overseers.

### Time of Relief

Multiple caregiving situation offered the family members some time of relief and rest from the caregiving responsibilities. Members of the family also stated that they filled in for others and they alternated in performing caregiving duties. Sometimes the ill person may rotate through the homes of other relatives. This enabled others to have some respite and this was important because it gave other caregivers some break and time off from caregiving responsibilities. Some relatives sometimes visited to come and assist in the care of the mentally ill person. The duties that relatives often assisted with included laundry and assisting in giving the ill person a bath; especially those who had problems with personal hygiene. Some remained with the ill person when the caregivers went somewhere.

> CG016: When I know I have to go somewhere, I ask my niece to remain with him, especially if I am going to spent a night there.
>
> CG009: During the time when there are plenty of melons and corn at the lands she goes there to stay with her sister. Sometimes she helps work in the fields but when she is not well she destroys crops and we bring her to Gaborone.

### Abundant and Limited Choices

The multiple caregiving situations had numerous choices, options, and flexibilities. Members of a family could make choices as to who should assume the responsibilities of caregiving. Similarly, these choices could also be limited in these situations because sometimes none of the family members felt responsible to assume the caregiving roles. It was observed that sometimes where there were many people some took advantage of others. Therefore, multiple caegiving situations do not necessarily guarantee abundant choices. There are several caregivers who had to leave their employment not because there was nobody to assume caregiving responsibilities, but because those other family members were not willing to do so e.g., C007, CG009.

### Gender, Power Relations, and Dynamics

The relationships of the caregiver to the ill person to some extent determined the power relations and dynamics in the caregiving situations. Gender relations also played an important and influential role in the caregiving situations. Data indicated that male caregivers seemed to have more power and control of the caregiving situation than their female counterparts irrespective of the sex of the ill person they cared for. They set well defined limits of care for the sick person by stating things they were be able to provide.

> CG005: (Male) You see, I am struggling even to feed them. As far as cigarettes, I can't buy them. At least I should make sure he eats regularly, keeps some standard of cleanliness, and should take his medications and go for his check ups.

The male caregivers possessed power and authority because they made the necessary decisions about the care of the mentally ill persons. They defined caregiving as providing for the mentally ill persons and other dependents in the home. They used phrases like "I give them money to buy whatever they needed and that was the care I provided or I contribute and share in the care by providing material assistance and money." To them, caregiving meant provision of financial and material support for their families. This view differed with their female counterparts who stated the actual activities they performed, such as providing for basic needs , supervising the ill person and ensuring that he/she took medications. The females actually enumerated the activities that they engaged in to administer care. Male caregivers had certain expectations for the female ill person they cared for. They expected them to perform household chores like any other woman. These expectations that they had for the female ill persons overrode their ill health. In situations where both males and females shared caregiving responsibilities, the male persons still saw themselves as decision makers and providers. Male caregivers also saw themselves as mediators in the caregiving situations.

> CG003: When I am around I talk to her and she listens because sometimes she gets angry with her mother and she can't manage her. But she would listen to what I tell her.

## Caregiver Perceptions about Mental Illness, Hope for Recovery, and Caregiving Situation

Caregiver perceptions referred to the meanings and interpretations that caregivers attached to mental illness, their hope for recovery, and the caregiving situation. These meanings were from the point of view of the caregivers themselves. The meanings and perceptions also influenced their course of action and their health seeking behaviors.

### Perception of Mental Illness

Perception of mental illness is influenced by the beliefs that the caregivers have about its causes. These beliefs entailed how the caregivers defined the mental illness. The concept of mental illness was described as unidimensional entity. The caregivers saw this illness as a disease that affected the head or the mind (*bolwetse ba tlhogo or bolwetse ba tlhaloganyo*).

The causes of mental illness on the other hand were described as having a multidimensional causality. They were enumerated as witchcraft, disregarding taboos or could result from punishment from the ancestors. Some caregivers stated that it could result due to stress, trauma, aging, and loss of an object. The disease is believed to be complex because it is not tangible when it is compared with other illnesses. It was described as "invisible" (in vivo code). Some caregivers perceived mental illness to be an illness just like any other illness, except that, sadly, one could not explain it the same way as one would explain a lesion or a wound which could be located somewhere. "Mental illness is invisible," commented one caregiver. This explanation testifies to the complexity and abstractness of this illness and hence the difficulty in understanding it.

> CG005: You see I don't know how you take this illness, if I remember my own mother had this illness (*bolwetse ba tlhaloganyo*) in so much that our family nearly had a stigma that we have this illness. My eldest brother too had this illness but his was like a nervous breakdown. He was an English master that man. So he was popular, giving children lessons for form five (upper high school) and trying to get a university degree. I think that was too much for one head and it gave him a nervous breakdown. I don't know what his kind of illness was much as his mother had it. But I think it was a nervous breakdown. My younger brother was a boxer and fought somebody who was heavy weight so I think he got injured. He told me that man hit him so bad that he felt his brain shake. As I am talking to you now he is mentally ill. His illness started in the 70's or 80's and I remember he told me this boxing story long before he fell ill, so I think his came from the boxing. In my relatives (*Lesika*), when you reach the age of 70 they have some type of mental derangement.

> CG026: My neighbor is responsible for my son's illness. This woman wanted my son to marry her daughter but I refused because they were still both very young and going to school. That was how everything began. Every traditional healer I have been to has told me that she is the one who knows where this illness came from.

The causes of mental illness were also attributed to loss of a valued object, such as losing a child. Although the illness was described as affecting the head or mind, it manifested itself through problems affecting the heart. The caregivers stated that their ill relatives said they had palpitations (*pelo e itaya*), felt dizzy (*sedidi*), and headaches (*opiwa ke tlhogo*). The trajectory and the content of the symptoms were also described in ways that indicated changes occurring in the heart. Caregiver 019 when describing her daughter's mental illness stated that "her heart just changed" which could also describe the ill person change in the state of mood and feelings.

> CG019: She has been ill for a long time and it all started when her children died. They died soon after they were born and when she saw someone with a child, she would just change *(pelo ya gagwe e tlola a ba a chencha, e itaya)*, and have palpitations. She would complain of a headache and dizziness. At that time I thought it was because she did not have children but now she has one child. I guess she is not happy about just having one child or may be she envies her age mates who have many children.

The caregivers also understood that this illness could be exacerbated by drinking alcohol and taking habit forming drugs. Some caregivers described their relatives as reasoning and functioning better when they were hospitalized but once they came home they became worse because they drank beer and smoked *dagga*.

> CG006: When he is in Lobatse (Mental hospital) he is just okay but when he comes home he starts drinking alcohol and his illness comes back again. He is old and it is very difficult to tell him not to drink. He has these two rooms that are being rented out and when it is month end and he knows that rent has been paid he demands it. And if we refuse with it he becomes very angry with us. But when he takes the money he goes drinking.

> CG005: I don't know the sort of things that he does when his gone all day, he doesn't drink but one thing I know is that on many occasions I have had a funny smell, not that of cigarettes. I think it is dagga (*Matekwane)* and his doctor one time when I took him to the clinic told me that he

> smoked dagga and I agreed and the doctor told me that dagga is dangerous.

> CG028: He is just a pleasant person because he is not violent but the problem starts if he drinks beer. I don't like him to drink but he goes around and friends give him beer. When he has taken beer he becomes very talkative and I always worry because people who don't know him might get irritated and beat or harm him.

### Hope for Recovery

Recovering from mental illness was seen as very difficult because the course of the disease was highly unpredictable. One moment the person was okay and then suddenly the condition changed. However, caregivers were hopeful that their ill relatives would recover. Hope for recovery was mainly expressed by caregivers for young people. Hopefulness was shown by the caregivers' many tireless searches for alternative treatment. The caregivers had the vigor not give up hope. CG010 stated that somebody who took care of an ill person never got tired (*motho ga a oka ga a lape*). This could also mean not to lose hope. The desire to continue to search for treatment also demonstrated that the caregivers had hope that their relatives would get help and recover. Recovery from the illness was described by the families as seeing the ill persons revert back to their previous lifestyles and functional states. The caregivers wished to see their ill relatives doing things they used to do before they became ill.

> CG014: I have always wished that my uncle could do things he used to do. He worked for himself and took care of himself and now he has to be bought everything. This makes me very sad. He should be doing things for himself.

> CG005: My worry is that he has been ill for so long and he doesn't become better. I have met a number of cases where they start being wild initially or even uncontrollable, but as time goes on they become better. I have seen real mentally ill people (*ditsenwa tse di tsenwang tota*). This person would go around naked in public and I was surprised when he got a job and started working, a place to stay, and catching a bus and going to work

> just like any other people. I had expected such things to happen with him.

Recovery for the old mentally ill was not an expectation for the caregivers. The caregivers did not have any hopes that their ill relatives would recover. The old person had to be accepted as he/she was and people had to just learn how to live with this person. The person had to be accepted just as he/she is. The caregivers used expressions that symbolized acceptance and willingness to live with this person (*ke segole same , ke itlhobogile, ke beile fela mo Modimong).* However, this could also mean that they lost hope. The use of phrase I have left everything in hands of the God (*ke beile fela mo Modimong* and that they regard their parents as *Badimo* (ancestral spirits) indicate spiritual solace for the caregivers which assisted them to refine their feelings and thoughts to accept the caregiving responsibilities. The terms and phrases such as "does not have strength anymore," "he/she is old," "has no education and can't do anything now" or (no strength) (*ga gona tiro jaanong mo go ene* ) were used by caregivers to describe the loss of hope for recovery. However, the phrase "I have left everything in hands of the God" may also indicate mixed feelings and ambivalence about the caregiving situation. It could mean that the caregiver had despaired and totally given up hope about the situation.

### Perception of the Caregiving Situation

The caregiving situation was found by most caregivers to be a difficult task, hard, tough, burdensome and requiring too much responsibility. Most caregivers felt overwhelmed because they felt inadequate to effectively manage the situation. Several factors contribute to their feelings of inadequacy. Caregivers expressed lack of knowledge and information regarding their relatives' illness. They also lacked skills to efficiently provide care to their ill relatives. They felt incapable to remain at ease emotionally with their mentally ill relatives because they could not predict when things would change. They stated that the caregiving situation fluctuated so much and sometimes the changes were too sudden. The caregivers stated that in this situation they were never sure what direction things will take the following day.

The other reason why caregivers felt inadequate was the due to the lack of resources to provide sufficiently for their ill relatives. They repeatedly mentioned how demanding some of these ill relatives were. Their ill relatives demanded money from their families to buy beer and cigarettes. If their families failed to meet their demands, they sometimes became violent and aggressive. Thus disrupting the whole situation in the home. In an attempt to avoid such confrontations, the caregivers struggled beyond their means to meet these demands.

> CG026: I can't manage him because when he wants something and I am unable to give it to him, like cigarettes, he becomes angry with us and even violent. Last time he wanted money for cigarettes, when I said I didn't have any money, he broke the windows. He just becomes so angry if he can't get what he wants.

The caregiving situation sometimes was unmanageable, especially when the ill person's behavior was aberrant. This was when the ill person was verbally abusive, violent, and undressed in public. The caregivers described this situation as frustrating, embarrassing, and emotionally painful.

> CG010: There's never a time when you can say you have a handle on things. Some days okay things are fine but others things are stormy. Thing is you don't just know what happened and he starts to insult other people. This makes me feel so sad because even if I ask him not to do that, if it's really bad, it becomes even worse, he becomes even more abusive.

Caregivers often felt constrained, restricted, and inhibited by the caregiving situation. They no longer do the kinds of things they used to do. Their personal life became modified by the responsibility of caregiving. They mentioned that they had to adjust, rearrange, reorganize, and negotiate their personal needs with the caregiving responsibilities. Role negotiation and shifting resulted in limited personal activity. For example some caregivers had to relinquish their employment or negotiate for work schedules that could still allow them to continue with their caregiving responsibilities.

> CG007: I never go anywhere because I have to take my mother. Even when my friends come and want us to go somewhere I cannot because I know I have a responsibility.

> CG009: I left my job to come and live with my family to care for my mother. Her illness had become worse and she could no longer manage things as she used to, and my father is working so he could not manage as well.

Some caregivers described caregiving as something that commanded a great deal of responsibility and commitment. As a result, one could not ask anybody to step in for them. One caregiver succinctly put it as "something that cannot be relegated to anybody." Some caregivers saw it as an obligation and a social expectation to care for their ill relatives.

> CG003: We are alone in her care. Her brothers become too sad when they see her like this and are overcome by sorrow and this makes them unable to care for her. But we have to do it because there is nothing we can do. Perhaps is what God has given us and we can't chase her away. God gives in many ways and children are never the same. So it is our duty to care for her. We can't ask anybody and nobody can manage.

Adult children who cared for their parents saw caregiving as an obligation as well a pay back or reciprocation. They reciprocated for their upbringing with caregiving. They stated that society also expected them to take care of their parents. They regarded their parents as "*Badimo* " (ancestral spirits). *Badimo* in a Setswana culture are sacred, treated with respect and should always be obeyed.

> CG008: She is my God *(Ke Modimo wa me)* and she brought me up and so I should do everything I can for her. Even the Bible says we should respect our parents. Our father died and he had been taking care of her and we have to continue that.

Caregiving in married relationships was seen as fulfilling the requisites of a marital and contractual agreement. Those marriage vows exchanged earlier on in their lives were seen as binding. It could be concluded therefore, that prior relationship of the caregiver and ill person played a very significant role in determining the terms and the nature of caregiving.

> CG002 (male): I swore and said I will be there for her no matter what happens so I cannot expect somebody to do it for me and besides I am just alone. I have no mother and no sister.

## Stages of Caregiving Experiences

Experiences of caregiving refer to all those encounters which may include emotions, thoughts, interactions, and actions that characterized the caregiving situation. The experiences of caregiving were described in stages indicated the initial reactions or responses of the caregiver to the situation when a relative first became ill, help seeking behavior, and how they learned to live with situation. These experiences may also entail the actual feelings that the caregivers have about the caregiving situation.

### Initial Response

Caregivers responded in various ways to the illness of their relatives. When the relative first became ill, the caregivers got shocked, wondered in disbelief as to what might had happened to their loved one because suddenly they noticed a change in their relatives' behavior. The moment was characterized by confusion, disbelief and uncertainty. The situation could not be comprehended. It became disturbing, very painful and sad. The caregivers stated that they hurt so much inside. Some wondered what it was that they had done to deserve all this. They also wondered what might have caused the illness.

> CG016: I didn't understand what happened to my boy. At first he would seem to be like he was talking to himself. Sometimes he would be very quiet and keeping to himself. Before he became ill he smoked and drank beer but he would not utter a word. After he became ill he would not sleep at night....he would talk to himself and sing and if I asked why he was doing that he would say why am I listening. He would never talk to me like that. This made me very sad and it was painful to watch him do all that because he used to be a responsible and respectable person.

> CG005: Well, for me personally, much as it was something painful, I take mental illness is just like any other type of illness. It is a pity that you can't get the type of thing that you get with the type of person who has a wound. They apply some type of ointment and even improvement in condition you can see with your eyes. Now mental illness is invisible.

## Search for Help

The persistence and escalating problems eventually confirmed that there was a problem and this led to the caregiver seeking some help. The search for help was influenced by their belief about what caused the illness. Most caregivers believed that the illness of their relatives resulted from witchcraft. Caregivers stated that they consulted traditional healers first and when they realized that there was no improvement, they went for western treatment. Traditional healers often included bone casters, herbalists, spiritual healers and prophets. Some caregivers expressed the view that mental illness could only be cured by traditional healers.

> CG005: I personally believe that mental illness can only be cured by traditional doctors but it means you must work, travel and really look for a good one! I have not been able to do that because I am an old man and I don't have transport. But it needs a lot of work because these people are not easy to find.

Although the caregivers used the traditional healers as the first line of treatment, they also consulted the western doctors, especially when their relatives showed no improvement. Some caregivers reported that they noticed some improvement in their relatives' condition after taking them to western doctors for treatment. They nonetheless would still consult the traditional healers. Therefore, a back and forth movement was observed between the two systems. People in search of treatment often tried every alternative that might be available. The caregivers were desperate to understand what was actually going on. Mental illness was seen as a very complicated phenomenon to comprehend. The search for treatment therefore, was seen as an attempt to find somebody who could explain to them what was happening.

> CG003: When she first became ill we took her to traditional healers (*ngaka ya setswana*) and spiritual healers (*Baporofiti*) but there was no improvement. Then we took her to Lobatse (Mental Hospital). She was admitted there and we saw some improvement. When she was discharged she was just like we knew her from before.
>
> CG006: We have tried everything, but with traditional healing, there was no progress and we resorted to the western treatment. He could be doing better but the problem is that he drinks a lot. When he is in Lobatse he is just okay. But when he comes home he starts drinking beer and this makes the illness come back.
>
> CG015: We once tried traditional healers but there was no improvement. But now we use both traditional and western treatment together.
>
> CG020: We have resorted to western treatment because traditional healers sometimes cheat us. They take our money without any improvement. But he has improved since we took him to the hospital.

### Endless Suffering

The caregivers expressed constant suffering, struggle and agony when living with a mentally ill person in the home. They grappled with illness episodes and events while they attempted to understand its nature. They were anguished and suffered perpetual distress related to persistent illness problems and the agonies that accompanied it. Some of the mentally ill became violent and made their relatives live under perpetual fear that they might hurt themselves or others.

The caregivers stated that they stayed under constant watch and lookout to prevent destruction and situations that would lead to it. Some were embarrassed by their ill relatives' behavior such as being verbally abusive and using vulgar language to other people. Some the ill relatives undressed in public. The caregivers described this situation as a very painful and difficult one to live with. It made them suffer emotionally and socially.

> CG009: I don't feel good when she insults and swears at other people. It hurts and embarrasses me because sometimes she insults my friends and this is painful. So I plead with her to stop doing that. Sometimes she listens and stops and turns to me and insults me.
>
> CG006: ...sometimes he does things that are bad and embarrassing; especially when there are children around. He takes off his clothes and walks around naked. You help him dress and in a little while he has taken off his clothes again. It becomes painful and sad because when people see him like that they would think we don't take good care of him.
>
> CG004: When I know things are not okay she would not allow anybody inside her room. You try to enter her room she will beat you up. Sometimes she becomes very violent that even nurse sometimes runs away and go and call the police to come and help. When she refuses people going into her room she does everything in there. Like you see now she has used that box as a toilet and we cannot take that away. It will smell like that until when she is better or tired and we can take it away.

### Living with it

The caregivers learned how to live with the situation. They learned how to survive in the midst of all these problems. They found specific ways of dealing with the situation that confronted them on a daily basis. They found and stuck to strategies that worked for them through trial and error.

Caregivers described many ways that they applied to manage the situation on to day to day basis. They stated that they deceived their ill relatives compassionately by playing tricks on them e.g., disguising medications and dissolving it in tea or soup. Sometimes they were dishonest with their ill relatives. At times caregivers infantilized their ill relatives and manipulated them. On other occasions they heightened the emotions of their ill relatives and beseeched them for a positive behavior and tried to make contact with them so that they refrained from undesirable acts. The caregivers stated that they found these specific strategies sometimes worked for them. However, one had to be patient because it took a tremendous length of time and effort to achieve a specific goal. Sometimes none of these strategies worked for them.

> CG009: Sometimes things are just okay but other days you never know what has happened. Sometimes I get to a point where I don't know what to do. If she is too ill there is no one who can manage her. No one can come into this yard. Then I would appeal beg and plead with her...I used to make her tea and put her tablets in the tea and she would drink it. But nowadays she questions why I like making her tea what is it that I put in her tee. Sometime she says I want to poison her and refuses to drink the tea. Then I inform the nurses that she has not taken her tablets and they come and inject her.

> CG020: He likes to have something salty and we make him some soup and put the tablets in the soup and drinks it because you can't give him the tablets , he knows their color. We make sure he takes his tablets...what is funny is that if he goes to the hospital for a different illness he will take his medicines well but these ones he refuses because he says they are for mentally ill persons. He will tell you those ones I don't want. And I tell him they are for waist ache/backache *(letheka)* and if he takes them he will feel better. Sometimes he takes them but at times he refuses completely.

Caregiver experiences occurred under different conditions and circumstances. The context of the situation was determined by the health status of the of the ill person and the problems that the caregivers had to deal with at that particular time. If the mentally ill was severely affected, the experiences of the caregivers intensified. Some of the experiences were cyclic in nature because they keep on recurring. The unpredictable nature of the illness also made these experiences to be on going and continuous.

## Caregiving Demands

The caregivers expressed a myriad of concerns about the caregiving situation. Caregiving demands refer to those factors that hindered the effective provision of care to the mentally ill by their relatives. There were demands that had to do with the caregivers themselves, those related to the ill person, demands that were created by the ineffective health care services that the ill relative received, and those that related to the community in general.

### Personal Demands

At personal level, the caregivers reported that the mentally ill drained them physically, psychologically, emotionally and materially. They felt inadequate to care for their ill relatives because they did not understand their behaviors. They stated that the ill persons were very difficult to control. Most of the urban recipients refused to go for check ups and would not take their medications. It was frustrating for caregivers to be in a situation that they could not control and manage. The caregivers reported that in most instances their ill relatives would manipulate them and threaten them to get anything they wanted. Therefore, in most instances, the caregivers would compromise in order to avoid explosive situations.

> CG025: ...these people are easy to take care of. Sometimes things are okay and he takes his treatment well. The next thing he refuses the tablets and even going for check ups. He is so difficult at times I wonder what had now gone wrong. He demands me to buy him cigarettes and when I tell him I don't have money he becomes angry and even throws things around. Last time I told him I didn't have money he broke the windows.

> CG009: There are days when things don't go okay. She would be very busy wanting to do this and that. Sometimes she can just take things out of the house, throw them outside and when I ask why she is doing that she becomes angry and starts scolding and insulting everyone even those passing by. I now know when it is going to be a bad day. She would start by talking to herself as if she is angry about something *(a omana fela)*. This makes me to feel helpless sometimes because I don't know what to do.
>
> CG006: It is very difficult to control a big person like him. It's not possible because even if he is ill he is still a big person. You can't tell him not do something, he just does it! You can't tell him not go anywhere like a small child, he just goes anywhere he likes. And it's painful because it's not that he doesn't listen but it's because he is sick.

The inadequate feelings also arose from the ambiguous nature of the illness. It is very complex and its course erratic. Even when their ill relatives improved, the stability was shortlived. This is a difficult situation to live with for the entire life.

### Demands Related to the Ill Person

The caregivers also expressed demands that were brought about by the ill person. They were deeply concerned about the illnesses their relatives were having. They worried because ill the person did not improve. They stated that they were always grieving about the situation of their relatives because they were not getting better and this was a permanent loss that they had to live with. They missed the essential person that used to be and that could have been. Their grief was accentuated by the fact that they knew the persons before they became ill and had this good history about the person. They knew their abilities and ambitions that had it not been for the illness their ill relatives would be far along with their lives. The ill person' ability to love and to work was gone and what remained were the sorrowful and painful reminders to the family of what had been lost. The grieving was continuous and unending.

The caregivers also expressed great concerns about the security of their ill relatives. The mentally ill living in the community were not safe because some of them wandered around and idle because it was very difficult for their relatives to control them. This situation rendered them vulnerable and susceptible to hazards in the community environment such as engaging in socially undesirable habits such as drinking alcohol and using habit forming drugs, such as dagga or marijuana. Some of the mentally ill persons left their homes in the morning and returned late at night. This predisposed them to the danger of being harmed. Being raped has very serious implications on the health status of these mentally ill persons nowadays because of the scourge of AIDS. The susceptibility of their relatives to the dangers in the environment made the caregivers to live under perpetual fear.

> CG001: She is gone all day and comes home very late at night. I fear for her because it is dangerous to move around at night and she is a woman. She can get raped or killed. I tell her how unsafe it is to move at night but does she listen?

> CG005: I worry a lot about the fact that he is gone all day. He goes from morning until late at night, and you see when a person is gone and you don't know where he is, you get disturbed. Sometimes it becomes difficult for me to fall asleep before he comes, and you see I am an old man who has had a stroke, I need my sleep. And you know when he is gone all day, you don't know the kinds of things he does. I suspect that he smokes dagga because sometimes I smell some funny smoke, not that of cigarettes, I used to smoke too a long time ago when I was still a young man.

> CG006: He is a big person and you can't tell him not to go anywhere. You see him at the next door neighbors and after sometime he is gone and comes back drunk. And once he drinks the illness comes. If he could stay away from drinking alcohol. It is really a problem.

Demands Related to Formal Services

Caregivers expressed a great dissatisfaction and resentment to the general services their relatives received. They were not happy with the services nurses, community workers, and social workers provided. They reported that nurses did not involve them in the care of their relatives and never explained anything to them pertaining to the illness, treatment, care, and management of their relatives. The caregivers of ill relatives who went for check ups regularly complained that the nurses never visited them at home. They mentioned that the only time they saw nurses was when there was a crisis situation. This was when their relative had relapsed. The situation was stressful because the caregivers felt abandoned by the health providers.

> CG002: The nurses don't come here, she is the one who goes to them. They will only come if you called them that today the ill person is sick. Otherwise they don't come here.

> CG026: I have given up on the community workers and nurses because when I went there to get help they said they will come here and assess to see if he can be registered for food rations. They have never come here and I asked the nurses when they come here to help him get something but up to now nothing has come up. I just gave up and I don't ask for that anymore.

The sentiments expressed by the caregivers were validated on field observations when the researcher accompanied nurses during home visits. It was found that nurses spent brief periods with the families and gave them very little education. In most instances, the nurses focused on the ill person and excluded the entire family. For example, the families mentioned that the nurse would just come and talk to the ill person and would not ask them how the ill person was doing. Some stated that they would impose and tell the nurses how their relative was doing.

> CG029: Nurses come here to give him his treatment but they never even talk to us unless if you felt you need to tell them how he was doing.

This was actually observed when the researcher accompanied the nurses on home visits. The nurse would greet the family and ask where the ill person was and would go to him or her and administer whatever medication and then leave. In one instance the ill person was inside the house and the caregiver was doing laundry outside, and we just went in and talked to the ill person and left without involving the mother.

It was also observed that the nurses visited families whose ill relatives were not taking treatment. The families whose ill member went for regular check ups were never visited at all.

> CG005: He goes for check ups and the nurses don't come here. I have never seen them. Just even to come and check on us and see how we are doing. they don't come. They are not like the ones in South Africa, they used to come and check on me after I had the stroke. I don't mean that they should come every month at least once every three months would be something. Because they don't visit us if they could at least give us some reading materials about this illness, then I could at least look up some things myself. But there is just nothing.

The families who were visited still felt left out and uninvolved in the care of their ill relatives. They reported that the nurses just concentrated on the ill relatives and excluded them from the scene. They stated that the nurses were just concerned about "their patient" (meaning the ill person).

> CG004: ...they come here and inject her but they never say anything to us. They are just concerned about their patient. Even the tablets they gave her I don't know what they do but they said that she should take them only when she gets cramps or saliva drools from her mouth.

One caregiver mentioned that she never saw the nurses because they came when she was at work. Therefore, she checked the card to see when next they were going to come so that she reminded the ill relatives. This was a clear indication of conflicting schedules of nurse and the caregiver.

> CG001: I don't see them at all because they come when I am at work. So I read cards and see when next they will come.

In rural area where part of the sample was selected, participants mentioned that nurses never conducted any home visits at all.

> CG023: No, the nurses don't visit us in our homes. I heard that at one time they used to do that but I have never seen that myself. Perhaps, there are some who are visited, I don't know but they have never come here. Even my sister there has never told me that nurses visited them. You are the first person to have come to talk to me about her care. I have gone to our council representative to tell her about our problems, but she hasn't done anything.

### Demands Related the Community

Caregivers reported that the communities they lived in were not at all concerned about the welfare of the mentally ill. This was demonstrated by the lack of community resources such as recreation, rehabilitation, and vocational resources. This concern was also raised by Kgosidintsi (1990) and Mantswe (1994). In Botswana there are absolutely no community resources, even after almost a decade and half since the inception of community mental health care. This has had very serious implications for the successful implementation of the community mental health program.

> CG003: The community is supposed to provide resources for these people but apparently the community is just ignoring them. There is nobody who can provide us with resources (*ditlamelo*) if we can't stand and join hands and work together in this illness as nation. It means the mentally ill persons will really be neglected (*ba latlhegile*). People are doing something for the blind, there is something that is being done for them. So with the mentally ill they are just neglected. The more we ignore these people the more their illness will become worse. So the community should stand up and take care of these people. Schools must be build just like there are schools for the blind where they can learn some skills like art, craft work and perhaps be able to earn a living. We know that here without any skill of some kind and education, it's difficult to get a job.

## Role Adjustment/Role Reorganization

### Accommodating the New Role

The caregivers also had to change and shift their roles to accommodate the new one. They learned to perform in their new role. Some caregivers worked hard to negotiate their work schedules or completely relinquished their work to be able to provide care to their ill relatives. This was a tremendous sacrifice on the part of the caregivers. It should be noted however, that very few employment sectors in Botswana can offer flexible work schedules.

Previous literature from the US reported differences in social limitations between females and males (Kessler, 1984; Miller & Montgomery, 1990). Contrary to these previous findings, both males and female caregivers in this study reported negotiation and/or termination of personal activity to assume and perform caregiving duties.

> CG002 (male): I don't do things I used to do because I take care of her and I am just by myself. At work, I have to be away to take her to the clinic when she is sick. My job requires me to work outside sometimes like Kanye or places like Mahalapye and when I am there I worry because I don't know if things are okay at home; she might be sick. I talked to my boss so that I should not go far because of her.
>
> CG003 (male): I work as a night watchman and I asked to work nights only so that I could be around during the day because when she is sick and I talk to her she listens. The mother cannot manage her sometimes.
>
> CG007: I worked, I used to work but I left my job because she fell sick. I felt that she needed somebody to be around when she falls . Somebody should be around to help her. I was afraid that if she falls alone she might injure herself because she falls on her arms and I make her lie properly.

## Caregiving Supportive Activities

Caregiver supportive activities refer to those activities that caregivers engaged in to sustain and maintain their ill relatives. These supportive activities included provision of basic needs, general supervision, and maintenance of the ill persons' social welfare.

### Providing for Basic Needs

The caregivers reported their caregiving activities to include provision of basic needs, general supervisory skills, and interactional skills. The basic needs that they provided for include food, clothing, shelter and anything that the ill person needed. They had to make sure that their ill relative had a good meal before they took medications. The caregivers stated that they observed that their ill relatives ate a lot. This was a problem for them because most families were unable to provide adequate food resources for their ill relatives.

> CG003: Problems that we face have to do with giving enough to eat. This illness is dangerous just like its treatment. She would not agree to take tablets before eating and we are struggling to provide food for her. She eats a lot and tells us that these tablets make her eat a lot. Sometimes she becomes angry because she says in Lobatse they know when to give them tablets and when to give them food but at home we expect her to take her tablets before she eats something. Sometimes we go all day without food and mostly we cook once a day and so it means for her goes really hungry. But we can't afford.

> CG006: Often times he complains that we don't take good care of him because we can't give him enough food. But it's because we don't have money to buy food because in town everything is bought. He always tells us how they are well cared for in the hospital because they have enough to eat and I believe him because when he comes from there he is always looking good and gains weight there. But when he comes here he loses it because we can't provide the kind of food he says they eat there. Sometimes he would want cornflakes and milk and when you give him porridge he refuses to eat it. But you see we can't afford cornflakes because again you have to buy milk. So all the things they give them there are things we can't afford.

The caregivers also mentioned that they provided shelter for their ill relatives. Almost all of the mentally ill in this study did not own a home. Most lived with their parents or relatives.

> CG010: You know, he is in a stage where he could be having his own house, family and children, but he can't because whose daughter can marry someone like him. He had a plot but he can't build it now. His life is over. I wanted to build so that it could be rented and help in maintaining him because I can't even afford to clothe him. Men's clothes are very expensive.

Some caregivers reported they had to make decisions on behalf of the ill person. They acted for and on behalf of the ill person. This concern was mostly expressed by caregivers who took care of the female ill persons who were still having their menstrual periods. The caregivers of the women stated that they had to take care of their ill person's personal hygiene that is, assisting them in keeping clean and changed when it was necessary. The caregivers expressed a lot of frustration, emotional pain, and sadness to be still involved in this stage when they themselves had reached menopause. According to the Setswana culture, it is considered a rites de passage to reach menopause and having attained a certain social status. To be still involved in the menstrual process of their ill daughters can be seen as having regressed and can be very frustrating and very embarrassing.

> CG001: I do everything for them. I cook, wash clothes, warm water for them to wash. They just sleep all day and do nothing and it is not good for them, I talked and have given up. I go to work and when I come from work I find nothing done. Even when they are having their periods they can't wash their underwear and I have to do that because they stain their clothes and it is bad and embarrassing.

> CG019: When she is having her monthly period (*kgwedi*), I wash her and change her because she doesn't know if it is bad to stain her dress. You see, if people found her with stains they will ask themselves where her mother is and I long finished this and I feel sad and ashamed to be still doing this.

Most caregivers were generally concerned more about the personal hygiene of their ill relatives because the mentally ill neglected this area. They showed no concern for physical appearance and cleanliness and this was often embarrassing to the family. They had to be reminded all the time that they had to bathe and to change into clean clothes. Sometimes the ill persons just refuse to yield to the request of their family members. This often resulted in conflict between the caregivers and their ill persons.

> CG005: The problem we have with him is his personal hygiene. You have to tell him to brush his teeth and take a bath. Sometimes he cooperates and does that without any reminder. But sometimes, he

> becomes very uncooperative and we end up quarreling on that. He is a big person and if he does not taken a bath he smells unpleasant. If he goes out of the house without washing then we know he will not wash that day. Even his room, he cannot keep it tidy. I cannot clean his room for him. Last time, because of the unpleasant smell, I had to take out everything in that room to air it, but he became very offended. So to get him attend his personal hygiene is a real problem for us.

### General Supervision

The supervision encompasses making sure that ill person takes medications, remind her/him when it is time to go for check ups, evaluation of the ill person's functional level and behavior and plan for appropriate interventions; for example if the person started to show signs of relapse they secured help from the mental health professionals.

Some caregivers reported some difficulties in the supervision of their ill relatives in taking medications and going for check ups. They stated that their ill relatives sometimes refused to go for check ups and to take medication, but reported a positive response from the mental health nurse because they came and administered medications to their ill relatives at home. The lack of adherence to the health care regimen by mentally ill persons has made nurses follow these ill persons in their homes to administer long acting psychotropics. Over 90% of the urban sample have treatment administered to their ill relatives in the home. The rural sample had no choice but to ensure that their relatives had treatment because the nurses did not administer treatment in the homes.

## Support for the Caregiver

Caregivers expressed the lack of support at personal, family, and community levels. Caregivers lacked resources at the personal and family levels because most of them were unemployed. Some had to leave their employment in order to assume caregiving responsibilities and this impacted negatively on their support at both personal and family levels.

> CG007: I used to work but left my job to care for her. I realized that she needed someone to be with her all the time.
>
> CG009: I left my job to come and live with my family to care for my mother. Her illness had become worse and she could no longer manage things as she used to, and my father is working so he could not manage as well.
>
> CG010: I don't have anything like I used before he became ill. I can't sew and sell clothes anymore because that meant going to places where people are, around shops and so on and I can't leave him alone. I tried to continue with my sewing here in the home but things would stay here without being bought so I was losing because sometimes. And just because I needed money so badly I would sell them for cheap, so I stopped selling. We have been depending on his brother when he was working, now he isn't working anymore because their firm closed down.
>
> CG019: Because of her illness even if I plough, I can't take care of my crops just like a Motswana woman would do. She moves up and down, to the fields, then to the village, and I am forced to follow her around because she can't even do anything for herself. When can I get time to look after my fields? What worries me when she comes to the village is that he wanders around and so somebody needs to be around because it is dangerous for her. There is nothing that I do for myself because I am always watching her like she is my mirror (*Ke nna fela ke mo lebeletse e ka re ke seipone ke ipona ka ene* ).

The metaphor above explains the extent of how much the caregiver watches over their mentally ill relatives and how this interferes with their abilities in securing and mobilizing support resources.

> CG009: Taking care of my mother would not be so bad if only I would be able to provide her with things that she needs. But sometimes it becomes difficult because I can't give her things that she needs like tea and snuff. She likes tea very much and if there's no sugar and milk she becomes angry with us. The money that my father gives us is not enough to last the whole month.

The families lacked resources because they were greatly impoverished and they still had to bear the burden of caregiving without any assistance. It should be noted that in Botswana there are no social welfare programs to assist the families to effectively take care of their relatives. Although there is a welfare program for people who are destitute, it has not benefited the mentally ill. The families expressed a more dire need for material support than emotional support. Caregivers conceptualized support from a material point of view. It was evident that there was a great need for material commodities to assist the families to survive on a day to day basis.

> CG001: I don't need people to come here to ask me how I am doing and stuff like that. I need things, I need food and clothes. I am tired of people coming here and asking me questions like how are you doing and get nothing in return. The social workers (*Mma Boipelego*) came here and asked me the questions you are asking but I never saw the results. They just get deceived when they see this house and they think I have money. It is not my house, it's my son's.

Some families had as their sources of support their adult children and siblings of the mentally ill but the resources were always over stretched because the families were too large with many dependents.

> CG005: His sister occasionally do give him something like buying him some clothes. Sometimes they buy us food, but we don't expect them to do thing s for us all the time because they have their own homes as well, but they help where they can.

> CG028: My children are the ones who provide for me. But right now things are difficult because my two sons have been laid off. Now it's my daughter who is working and we all depend on her. It's too much for her because she doesn't make a lot of money. I try to sell some stuff so that at least we can get some tea and soap.

> CG026: I have one daughter whom I really depend on. She is the one who does everything for us, even this extension of the house, it's her. My other children are very irresponsible. I can't even send them to do anything for me. They are not willing to listen to anybody and yet they stay here with us.

> CG006: My husband used to work and provided for us. But now he does not work any more. It is hard because we can't manage. We have no money and we have children to care for, so it's hard.

Some caregivers reported that their resources were depleted and exhausted by the many searches for treatment such as consulting traditional healers. Traditional health care as already mentioned, can be very expensive. Some families were involved in other commitments which hinder them from providing adequate resources for their family member.

> CG003: I am sure there is no place where we have not been. We have taken her all over, everywhere, because we thought she might get help. We don't have any money or cattle. We sold all our cattle to pay traditional healers. We are left with nothing.

> CG002: She was put on food rations and that used to help a lot. But they just took her off. I don't know why. These people eat a lot and the little money that we have cannot help. At least if she could be given food rations until I complete this house.

Although caregivers received some monetary support from their relatives, they mentioned that the support was not on regular basis. It was sometimes inconsistent and uncertain.

> CG028: When children give you, you just take whatever you are given and you can't say I want so much. Sometimes they don't give you and you can't ask why haven't they given you because you know they might have some commitments. They have to buy things for themselves too.

> CG008: Her children do provide for even if they don't give her all the time because I mean we can't sleep without a meal. My sister who lives here with us is the one whom we really depend on, especially for food and things that we may need on a day to day basis.

As it has been already stated, there are no rehabilitation and vocational resources and programs for the mentally ill in Botswana. The lack of structured environment in the community leave the mentally ill to idle and wander around with resultant use and abuse of substances such as alcohol and dagga smoking.

> CG005: I think there is no democracy because if there was then something could have been done for these people. There is absolutely nothing in the community for them to do. They just idle. I wish there could be

> recreation and some vocational centers where they could be kept busy all day; perhaps this could minimize their loitering. We parents have nothing to give them as you can see; we have our electricity cut because we have not paid for several months. I am sure the water will be cut too if we don't pay soon.

Caregiver support was seen as either formal or informal. The informal support was provided by the family members, other relatives, and friends. Formal support was provided by nurses, social workers, community workers, and police.

> CG002: Nurses and community workers (*MmaBoipelego*) should be the ones to help us. She goes to them and tell them what she needs. With the hospital really there is no problem because you just call them on the phone and they come immediately. You'll just see a BX stopping here (BX refers to Botswana government vehicle). The difficult ones are *BommaBoipelego*. They don't know what they are doing. They will tell you she has children and she can't be put on food rations because her children ought to provide for her.

> CG010: Sometimes the nurses take too long to respond or may be don't have a vehicle, I just go to the police and they come here and take him to the hospital. Before he got a stroke he used to beat them but now he can't do that any more because his other arm doesn't function.

> CG006: Being near a police station really helps because I just go to them when he is sick. They now know him and when they see us they ask if we are having a problem and they'll take him to clinic there and there.

Information and knowledge about the disease were other areas that the families said were wanting. They expressed a need to understand mental illness, its causes, course, treatment and management. Families also wanted to acquire some skills related to the general management of their ill relatives' behavior. Most raised a concern that the nurses did not educate them about mental illness.

> CG005: If the department or unit in charge had pamphlets that would keep the families informed - better informed. Allright, even if the they are not literate, they can be visited like you are here now just to check on us. That could make a lot of difference for the guardians of ill persons because we will not feel left alone in the dark. I think there should be

> some kind of connection between the families and the nurses. The problem is that they want us to go to them and if we don't have money we can't go. It's a pula (pula is Botswana currency US $ 1: 4) to go and a pula to come back.

## Problems in the Caregiving Situation

Caregiving for the mentally ill can present with a host of problems. These problems stemmed from the disruptions in daily living patterns that could occur in the caregiving situations. The problems that were commonly expressed included unpredictability of the illness, disrupted family relations and interactions, disrupted households, and family conflicts.

### Unpredictability of the Illness

The caregivers expressed great concern on the unpredictability of mental illness. The course and outcome of the disease was always desolate. The fluctuations left the caregivers totally confused and disconcerted. They described their situation on a day to day basis. Even when there were moments of calmness and stability, there was always that reluctance to settle because time for relapse was unknown. The caregivers had a difficult time to plan for the future because they would not just know whether things will be feasible at that time.

> CG023: I can't work in my fields like I used to because if I plough and then she becomes ill I have to abandon my fields to be with her. Sometimes when we at the fields, she comes to stay in the village and I know she can't really manage things on her own.

> CG006: You see, I think his illness is too strong or severe now. You may think that he is okay and in a little while you don't what might have happened and he is sick again. Suddenly things change and he start behaving in a funny way. So we just live for today and we'll see what it will be like tomorrow.

When the person suddenly relapsed family relations, interactions and the household activities became disrupted. These cyclic occurrence of events also caused stagnation in personal and social development. It also impacted the support networks. This was clearly demonstrated in family group 4 where family relations were strained and future support for the ill person was in jeopardy. The difficulty to manage the ill member in this group left every one defeated in providing care.

### Disrupted Daily Patterns

Some caregivers reported disruption of their daily lives. They reported that when one took care of a mentally ill person, there was no definite pattern in the household. Some established norms were always interfered with and one never just knew what may happen next. The caregivers stated that the ill persons sometimes had awkward sleeping patterns. They slept during the day and at night when every one else wanted to sleep they were awake and disturbing them. As a resulted the family experienced disrupted sleeping patterns. Caregivers reported a general disrupted live in their homes because things have never just been the same.

> CG016: Sometimes he doesn't sleep during the night and that's when I know things may not be just be right. He sings or talks to himself the whole night. He talks so loudly that sometimes he wakes up the neighbors. This makes me so sad because I find myself helpless. Sometimes when I tell him not to make noise like that he says why do I bother listen to him.

> CG023: There are times when she doesn't sleep and she will get up and goes away and we are always fearful that she will get into some danger or she might get hurt. She used sleep with her grandmother but now I sleep with her because her grandmother is also not too well. She needs a good sleep. Sometimes she asks for snuff all night. Even if you give her some that will not satisfy her.

### Family Conflicts

Family conflicts sometimes occurred over the ill person's treatment and property. The conflict could either be between other members of the family or with the ill person. There were instances where family members did not agree on the treatment to be followed. Some members wanted traditional care while others preferred western care. This created conflict and impacted support to both the recipient and the caregiver. Conflict over the selection of a treatment modality was influenced by the person's set of beliefs and values. Some people wanted to stick to treatment that improved the ill person's condition while others strongly believed that their relatives were bewitched and therefore, wanted to consult the traditional healers.

> CG030: My brothers were the only people on whom I had depended but they wanted him to go to a traditional healer. But he had been there before and there was no improvement and I could see some improvement with the western treatment, so when I told them that I was still observing this treatment. They got angry with me saying that I didn't want him to be cured. But that was not what I was saying. I wanted to observe him for a while on the western treatment. Since then they don't want to help me, and they don't come here to see us. But they are his guardians or parents (*ke borraagwe*)

> CG012: He doesn't take his medication because he wants to consult a traditional doctor and we belong to the Zionist Church (ZCC) and we cannot use a traditional doctor (*ngaka ya Setswana*).

The above statements angered the ill person and he started pacing around and the situation became really tense. Due to their strong religious beliefs, the family members would not accede to the demands of the ill person. In this situation family interests conflicted and the ill person also refused to take his medication. The ill person was seen as being uncooperative by his family and his support was at stake because he depended on his them This situation presents a dilemma in caregiving of the mentally ill because although they might be adults, other people have to make decisions for them.

Property ownership was another area that resulted in conflicts in the family. Some mentally ill who previously owned property were incapable of managing it and someone had to do that on their behalf. Some mentally ill often felt cheated by their relatives. Property conflicts resulted over cattle and house ownership.

> CG006: He built this house while he was still strong because he worked. But now we mange it for him. We rent it so that we can be able to maintain him. But sometimes he becomes very mad with us because he thinks we cheat him and take his money. So demands the rent and when he does that we give it him. We instruct him to go and for the house at the council and he does that. After that he drinks all the money. And when he drinks he becomes sick again.

> CG010: This man has a plot (SHHA) and his uncle has build a house on it. I want it back because it would assist me in taking care of him. He also had cattle because his father left him some. But his uncles have taken them. So he is just like you see him. He has nothing and yet he had worked for himself to have some property. This has strained our relationships because I once reported the matter to the chief at home and he said he gave us a chance to amicably resolve it. But ever since then nothing has been done. We are even not in good talking terms.

## Caregiver Strengths and Capabilities

Caregivers of the mentally ill in this sample showed a number of strengths and capabilities that sustained them in the care of their ill relatives. The strengths were that as caregivers encountered and experienced hardships in the care of their mentally ill relatives, they grew, developed and became resilient. The caregiving situation was described as stressful and very demanding and it was particularly striking to see how these families lived positively and managed to survive on a day to day basis.

### Caregiver Qualities

Caregivers reported certain qualities that they thought a person providing care for a mentally ill in the home needed to possess. They enumerated the following qualities: having patience and time for the ill person, tolerance and compromise, ability to give special care, giving them love, careful communication with them, ability to exercise self discipline or self control, and treating the ill person like any other person without marginalizing him or her.

> CG003: People having this illness are difficult. You have to be patient with them, tolerate them, never argue with them, and exercise a lot of discipline within yourself *(boitshwaro)* because if you don't do that you can harm them. You should also be careful not compete with them and give them love and special care.

*Boitshwaro* means restraining oneself, controlling one's feelings and emotions and exercising enormous tolerance. Caregivers showed tremendous absorption of pain without being angry. The caregivers reported this skill to be a very difficult one to develop but it was necessary in the care of mentally ill persons.

### Ability to Problem Solve

The family caregivers also showed that they possessed some problem solving abilities. From previous descriptions, families faced multifaceted challenges and problems associated with the mental illness of their relatives. The problems that faced them included the need for understanding the illness, its treatment and management, inability to control their ill relatives, lack of resources, personal and social demands of caregiving, and lack of skills in the care of the mentally ill persons.

The caregivers have also shown an ability to manage and resolve conflicts. The conflict areas included time, conflict of relationships, conflict of ideas about help, and conflict of interest. When their time schedules conflicted, but they negotiated and rearranged them or relinquished an activity and chose one over another. In conflicting relationships, they encourage each other to talk over their differences. Conflicts of relationships between the caregivers and the ill person resulted when they called the police in times of crisis and they continued to live on despite these.

> CG005: Yes, I think that one best thing is my relationship with the sick person. You must sit down with him and talk things out so that you keep winning him towards you. Have time to talk with him so that he sees

> that there is somebody who cares about him. Be patient with him. We nearly had a bad relationship because one time when he was sick I called the police on him and that really strained our relationship because he accused me of committing him to a mental hospital.

Others had conflict of interest because they did not want their ill relatives to drink beer and yet they brewed it. They made available alternate environments for them so that they could continue with their income generating endeavors. This was particularly stated in group D where the family members preferred the ill person to stay at the fields to avoid access to alcohol.

Caregivers resolved some of their problems or found best ways of dealing with them and moved on with their lives. Some ensured that their ill relative took treatment by employing whatever strategy worked and survived on to day to day basis and managed to mobilized help in times of crisis.

### Encouragement and Resiliency

Encouragement and resiliency were shown by the hope that some of the families had. They have not given up hope about the illness of their relative. This was demonstrated by the continuous search for treatment that families engaged in. Resiliency was illustrated by the families bouncing back from very adverse situations.

## Coping Strategies in Caregiving Situations

The caregivers utilized a number of coping strategies in their caregiving endeavors. These strategies sustained them on a daily basis. These included: accepting, negotiating or shifting, accommodating and manipulating.

In accepting, the caregivers had to come to terms with the fact they had no choice but to assume responsibilities of caregiving. This is was the initial step or process that occurs. Negotiation relates to the shifting and shuffling of roles around to accommodate this new role. Negotiation and accommodating can be subsumed together although negotiation pertains to the arrangements and rearrangements that occur in the caregiving situation. Accommodation, though closely related to negotiation, means the caregivers reconciled and compromised their other roles so that they were in harmony or agreed with the dominating role. Caregivers reported relinquishing their jobs or changing their work schedules to fit the new role.

Caregivers manipulated the caregiving situation first for the good of their ill relatives and last for their own good. They played tricks, deceived their relatives compassionately, or simply became dishonest. This strategy was mostly employed when the ill relatives would not take their medications. Some caregivers dissolved the tablets in tea or soup to give their ill relatives to drink. In this deception, the goal of ensuring taking medication would be achieved. This was stated in group D where the caregiver used these manipulative techniques to disguise medication because the ill relative knew the color of the drugs and could identify that they were for treating mental illness.

> CG009: When she refuses her tablets, I put them in her tea and so when she drinks the tea, she takes them. ...when she refuses to go to the clinic I go and tell the nurses but I tell her I am going to buy her something. ...when I come with the nurses I drop off somewhere so that she doesn't realize that we were coming together. Then they give her treatment.

It is eminent that providing care for a mentally ill relative was a learning experience the family members. It assisted them to acquire some skills of caregiving from a practical point of view. They were in a better position to identify what worked and what did not.

## Conceptualization of the Caregiving Situation of the Mentally Ill in Botswana

### The Spider Web Metaphor

Conceptualization and interpretation of the caregiving situation presented by the voices of the caregivers is captured by the spider web metaphor. The caregivers described the caregiving situation as difficult, hard, tough, burdensome, having too many demands, and requiring too much responsibility. These descriptions of the situation by the caregivers were analyzed as forming a mental image of a spider web (see Figure 4.1). The spider web metaphor is utilized to conceptually capture the difficult and complex scenario of the caregiving of the mentally ill in Botswana. It depicts the degree of complexity and intricate nature of the situation as well the interelatedness of multiple concerns and contingencies. Once inside the web, leaving is very difficult if not impossible.

The caregivers have stated their frustrations, agonies, sufferings, and their perpetual struggles in the caregiving situation. The mentally ill persons with their entire family including caregivers can be seen as entangled and trapped in a very difficult situation in the middle of the web (*Ba tshwerwe ke bobi basegokgo tota*). Like a spider web which may increase in size, their problems may grow. The web can also decrease in size. Similarly, the problems of the caregivers can also decrease depending on the situational factors from the micro caregiving environment (including the health status of the recipient of care, support systems, encounters of caregiving, demands, relationships and interactions) and the macro environment (including social, political, economic, and cultural environment).

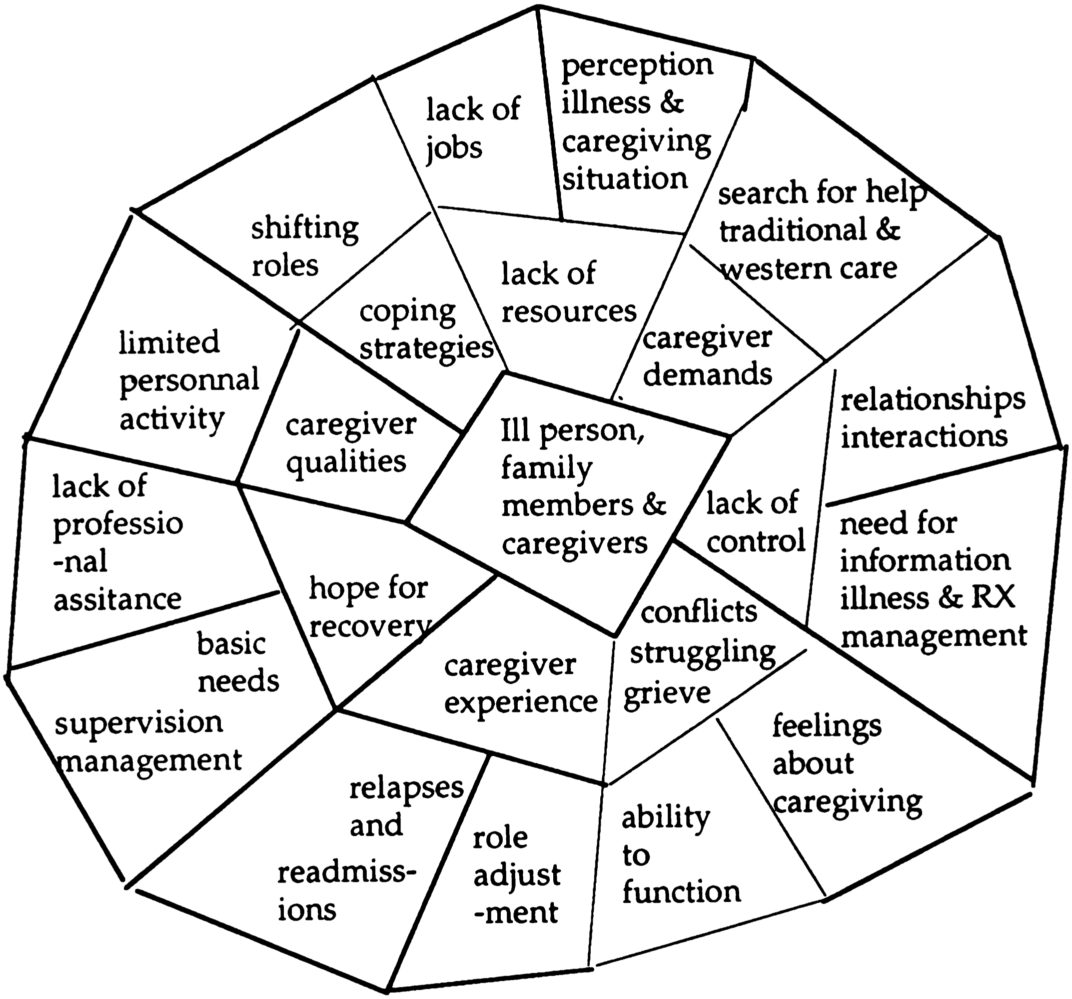
When the spider web increases in size, this signifies that the caregivers are unable to control the situation, but when it shrinks this means that they are able to control some aspects of the situation or their encounters are not overwhelming. To disentangle themselves, the caregivers utilize several coping strategies to overcome the problems of the caregiving. These include accepting the caregiving responsibilities, negotiating and shifting of roles in order to accommodate the new role, and manipulation of the situation sometimes through compassionate deceit to calm and win their ill relatives' desirable and positive behaviors.

Successful implementation of these coping strategies leads to the caregiver regaining a healthy functioning, being able to resolve problems and conflicts, and regaining resiliency within the situation. The conditions that make successful coping possible are relationships and interactions in the environment such as sharing of responsibility of caregiving, cooperating, and consultation. The condition of the recipient of care and the nature and extent of concrete available support resources also shape the degree of coping and the functional ability of the caregivers. These also shape the magnitude, extent, and the intensity of the caregiving situation.

The second part of the model illustrates how caregivers decipher the caregiving situation and select appropriate strategies to address the situation that is confronting them at a particular point in time (see Figure 4.2). Coping is not a one time event but must be accomplished daily, even many many times each day. Confronted by their own specific situations, the caregivers decipher whatever coping strategy is appropriate at that point in time to address the demands of the caregiving situation and this may lead to restoration of their strengths and ability to function or their depletion.

The last part of the model (see Figure 4.3) shows both the conditions that may determine the situation and the consequences. In most instances it is the health status of the recipient that dictates the actions and the coping strategies that will be utilized. Therefore, in a nutshell, the trajectory of the caregiving situation, coping strategies, and actions are dependent on the health status of the recipient of care, the relationships and interactions in the social environments, and situational factors such as support resources.

Figure 4.1 The Spider Web Metaphor of the Caregiving Situation of the Mentally Ill



# Negotiating the Caregiving Situation

## Components of the Model

The second model portrays how the caregivers negotiate the caregiving situation again and again and again. The model is composed of several intertwined composites which can be seen as making up the micro environment of the caregiving situation. These include the recipient of care and all his/her characteristics e.g., health condition, adherence to medications, and going for regular check ups. The caregiver(s) and other members of the family with their characteristics, health beliefs, size of the family, support, duration of care etc. The structural factors and the cultural context include resources, beliefs, values, and practices, places of residence, politics etc. The family members and caregivers are represented as "in between" recipients of care and the macro environment. This is so because they provide a protective cushion for the recipients of care from the harsh effects of the macro context. Caregivers mediated for their mentally ill relatives. They can also be seen as bridging the caregiving situation and holding the ill person within the social constructs. Their strategic position assists in striking a balance or creating a situation of tolerance between the recipient of care and their social environment.

Each caregiving situation is unique and specific and can be seen as a constraint and contained entity. It has components in the form of layers of concerns and issues which are portrayed as spiral and helical in nature. The convolution picture depicts the turbulent nature of the caregiving situation. The caregivers have described this situation as unpredictable, uncontrollable, and uncertain. Hence they are always cautious. The elements of the caregiving situation may include caregiver experiences, current perceptions of the caregiving situation and mental illness, caregiver feelings, caregiver received support, caregiver supportive activities, professional assistance, etc.

Caregiver experiences refer to the all encounters that caregivers go through in the caregiving situation. They may include interactions, actions, thoughts, and emotions characterizing a particular situation over time. These experiences can be described in stages which include initial reactions to the situation and illness episodes, health seeking behaviors, and learning to live with the situation.

Perceptions of the caregiving situation and mental illness refer to the meanings and interpretations that caregivers attached to mental illness, recovery, and the caregiving situation. These perceptions are influenced by the caregivers' belief system, family obligations, and expectations.

Caregiver feelings refer to largely to the emotional sensitivity that caregivers expressed about the caregiving situation. These may be directed towards themselves as they often times felt inadequate in providing care for their ill relatives. The feelings may also be directed towards the ill person, health services and the community at large.

Caregiver support refers to emotional support and material livelihood contributions that sustain, assist, and maintain the caregivers in providing care, often provided by others, both family and non-family. Caregiver supportive activities refer to those activities that caregivers engage in to adequately provide care for their ill relatives. They include material, emotional, physical, and social.

Caregiver demands refers to the problematic features inherent in balancing the role of the caregiver with other roles served within the family network. They can impact the caregivers' strengths and abilities and cause difficulties by preventing the caregivers from fully executing their roles.

The caregivers' background, meanings, history, experiences, perceptions, understanding of the illness, concerns, and demands comprised their "social worlds." Their coping and the negotiated caregiving situation is set up by these "social worlds." These "social worlds" are complex and unique to the people experiencing them.

## The Negotiation Process

To overcome the problems, the caregivers continuously negotiate and renegotiate the caregiving situation. The metaphorical representation of the spider web maps out the caregiving situation to establish and reaffirm the problems and needs at a particular point in time requiring immediate attention. This happens because caregivers present with diverse unique needs and problems. Once the caregiving situation is synthesized, each caregiver deciphers the caregiving situation according to what it means it to him/her and chooses to address the needs and problems that present the greatest threat. Therefore, caregivers deal with the caregiving situation in diverse ways according to their own logics of caregiving.

Once certain problems or needs are experienced, the caregivers select specific coping strategies to address the situation. Thus caregivers may select different coping strategies for different problems at different points in time in response to their constructions of the current situation. Notably, what works for one caregiver may not necessarily work for another.

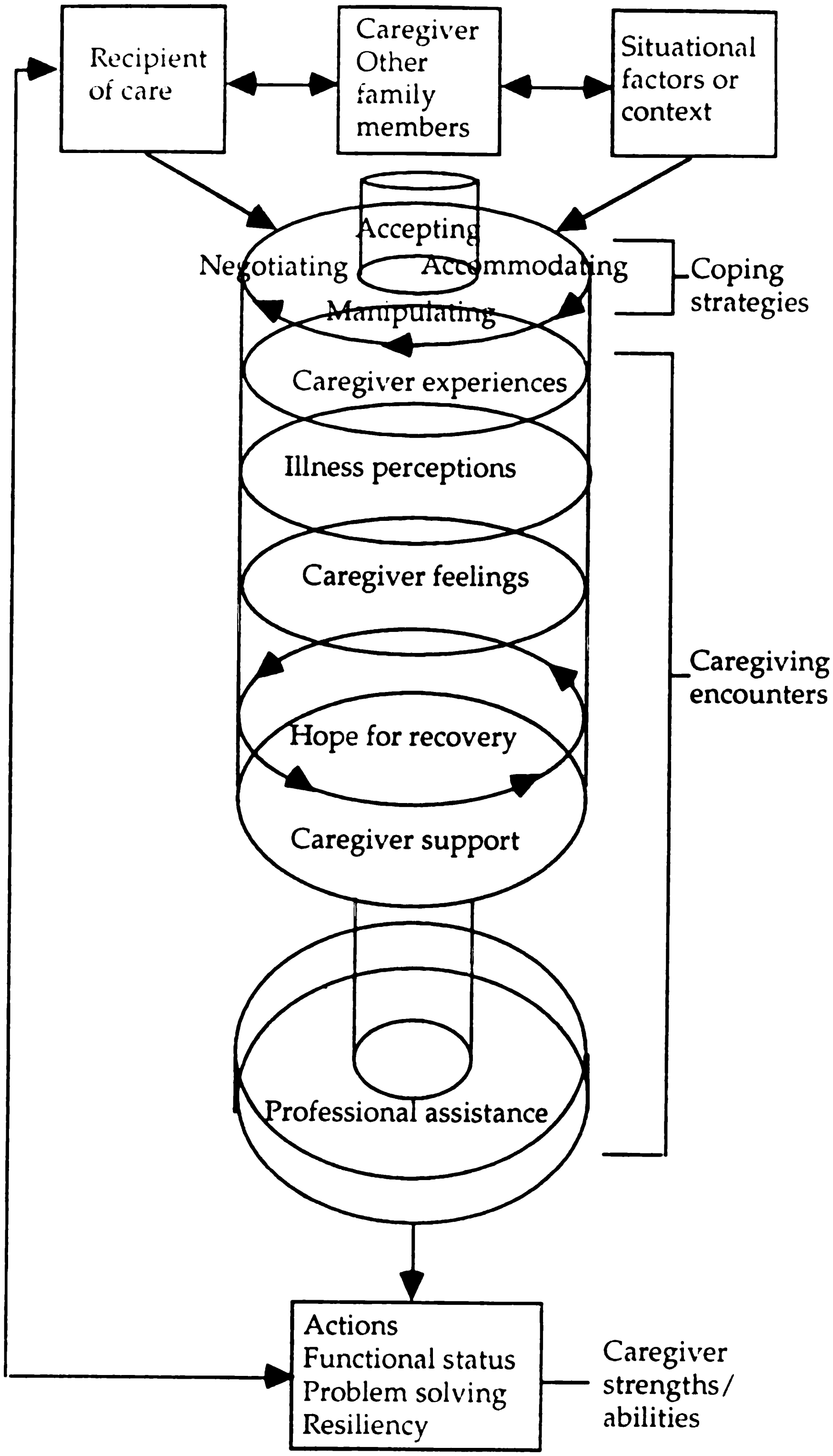
Different conditions may shape the selection of a particular coping strategy and actions. These conditions include the condition and health status of the recipient of care, relationships and interactions in the caregiving environment, and situational factors such as support resources. The conditions in the caregiving situation also shape the contingent actions in the ever-changing caregiving situation such as what type of help to seek out or search for. The caregiving actions, conditions and consequences, however, are deeply intertwined and they may be influenced by and influence one another.

The different layers indicate the different problems, needs, concerns, conditions, and consequences in the caregiving situation. Through the utilization of various coping strategies, the caregivers are able to pass these layers of encounters in order to regain control of the situation and functional abilities. The layered problems, conditions, and consequences in the caregiving situation can revolve and turn in different ways in actual practice, thereby reconfiguring the caregiving situation. This reconfiguration may either increase or decrease in complexity and intensity. The degree of complexity and intensity shape the control that the caregivers gain in the caregiving situation. The state of configuration shapes the actions, performance, and the direction of caregiving. This can be seeking and searching for more health care services within and beyond the boundaries or confines of the caregiving environment.

According to the model, professional assistance is detached from the rest of the spiral layers. This demonstrates the fact that caregivers sometimes may bypass the health care providers in meeting and addressing their needs. This may happen because caregivers have indicated some lack of involvement by the nurses in the care of their ill relatives. They also stated that they were dissatisfied with professional assistance.

This scenario challenges both the families and the health providers to attempt to fully comprehend each caregiving situation through thorough family and situational assessments, choosing the most appropriate coping strategies and actions that can benefit those involved in these specific and ever changing situations. The repeated actions, conditions, consequences, and coping strategies form meaningful ways to enable the caregivers to understand their situations. Finally, the effectiveness of the actions, the extent of control, and degree of resiliency will shape the direction and further processes in the caregiving situation. The model (see Figure 4.2) illustrates this proposed theoretical framework for analyzing and understanding the caregiving situation in Botswana.

Figure 4.2 Model on Negotiating Caregiving Situations of the Mentally Ill in Botswana



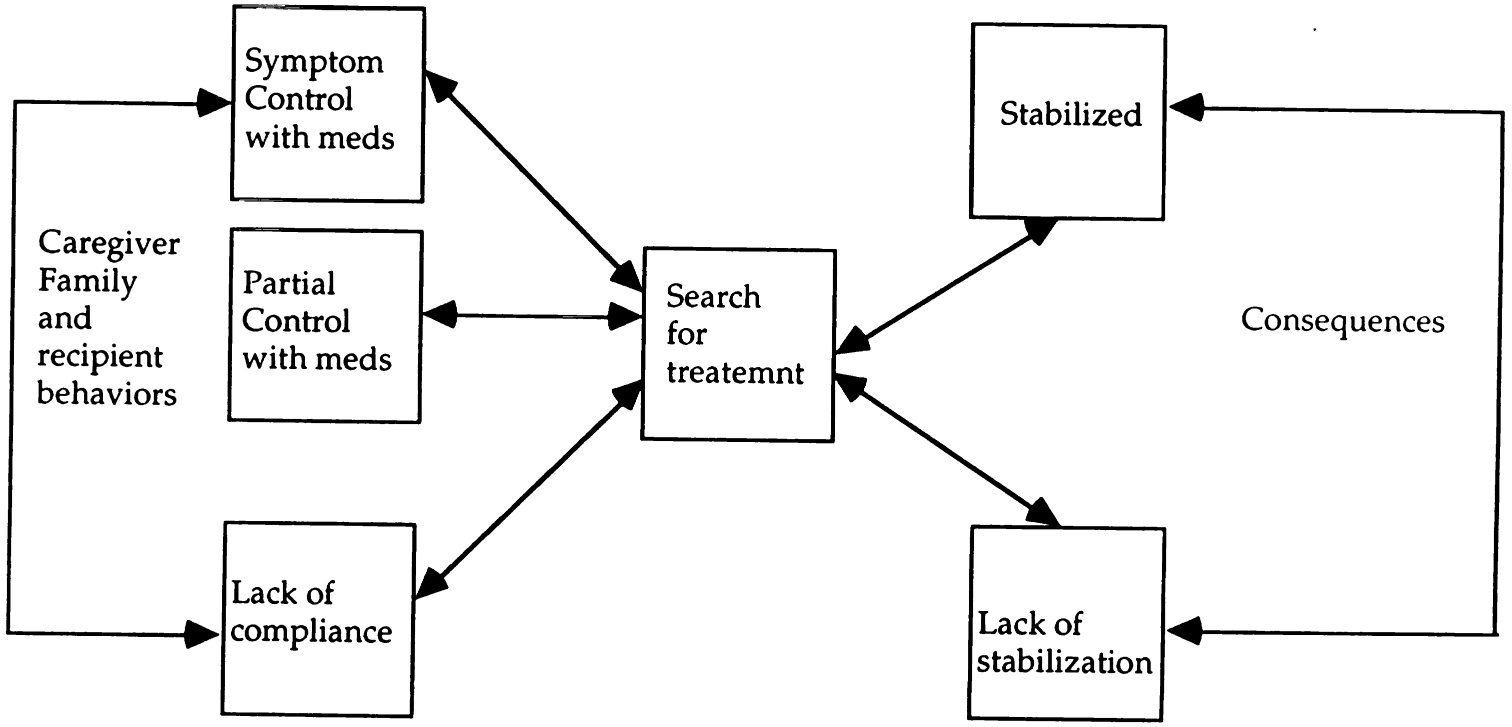


Figure 4.3 Caregiver Model Depicting Conditions and Consequences

## Social Processes

Several basic social processes have been identified in the caregiving situations of the mentally ill in Botswana. These include enmeshment, ongoing occurrences, unending or unaccomplished care, and confinement or inescapable burden.

The process of enmeshment refers to the entanglement and trapping nature of the caregiving situation. The families and their mentally ill relatives are engulfed by the caregiving situation. Consequently there is some loss of control over it. In an attempt to regain control, the caregivers utilize coping strategies of accepting, negotiating, accommodating, and manipulating. The coping strategies assist the caregivers to deal with the problems that they encounter in the caregiving situation.

Ongoing occurrences refer to the repeated problems and events in the caregiving situation. These occurrences may not appear once but, recur in new iterations because of the unpredictable and uncertain nature of the caregiving situation which is intricately influenced by the illness episodes and by the vagaries of daily life. The ongoing occurrences may take different turns and spins in different directions, hence presenting differently at particular points in time. Coping is seen as continuous and not as a "once and for all" task. It is an activity that takes place all the time in varying and often unpredictable forms.

Unending or unaccomplished care refers to the lack of closure in the caregiving situation of mentally ill persons. The caregiving situation of the mentally ill is ongoing, and sometimes reverting to initial stages. The ultimate goal is not to accomplish set tasks, but rather, for the caregivers to learn how to survive within the situation on day to day basis.

Confinement or inescapable burden refers to the difficulty of the caregivers to free themselves of the caregiving situation. Once the caregivers are in this situation, it is almost impossible to get out of it. The caregivers are physically and emotionally as well as culturally immersed in the caregiving situation because of their kinship ties. This explains their loss of freedom to engage in their previous personal activities after they have assumed the caregiving roles. They cannot avoid or circumvent the situation because of its numerous difficulties and inherent problems. It is a "baggage" of commitments that they have to carry for their entire lives as members of that particular family and kingroup.

## Properties, Attributes, and Conditions

### Caregiver Situation

- Caregiver experiences
- Caregiver belief system
- Caregiver feelings
- Supportive activities
- Caregiver received support
- Caregiver demands
- Hope for Recovery
- Perception of mental illness and caregiving situation
- Contact with health providers

### Coping Strategies of Caregivers

- Accepting
- Negotiating
- Accommodating
- Manipulating through compassionate deceit

### Caregiver Strengths/Abilities/Actions

Functional status

Problem-solving ability

Health seeking behaviors

Resiliency and flexibility

Conditions and Consequences

Health status of recipient of care

Interactions and relationships

Support resources

Situational factors e.g., employment, beliefs, residence, politics, and economy.

# CHAPTER FIVE: DISCUSSION OF THE FINDINGS

The central focus of this study was to investigate the caregiving situation of families with a mentally ill relative at home in Botswana from the perspective of the families themselves. This focus stemmed from the inadequacies identified in the existing literature and the paucity of information on this subject in Botswana . The study investigated the perceptions of families in Botswana about care of the mentally ill relatives at home, their experiences in the care of these mentally ill relatives, their supports and available support interventions, how these have been relevant and appropriate in addressing the caregivers' needs, the sectors (formal and informal) that were instrumental in assisting the families to cope with the caregiving situation, community resources, and lastly the contributions of other family members in multiple caregiving situations.

In this chapter, I will present demographic information of the caregivers and the recipients. This information is very important because it contributes significantly to the general outcome and quality of life and the management of the caregiving situation.

Second, the themes and concepts that emerged from the analysis of data will be discussed. These include caregiver experiences, feelings, hope for recovery, demands, support, caregiving activities, problems and concerns, coping strategies, and the strengths that family caregivers employed to survive on a day to day basis.

## Demographic Characteristics

### Age and Sex

The demographic characteristics of the caregivers and recipients converge with those in previous caregiving literature. Caregivers in this sample were mostly women (86%) (Baillie, et al., 1989; Guberman et al., 1992; Howard, 1994;

Jones, et al., 1995; Mintzer, et al., 1992; Robinson, 1989) and closely related to mentally ill persons (Mogorosi, 1994). Their ages ranged between 21 and 74 with 67% being 50 years and over (Reinhard, 1994). This is in contrast to the age of the recipients whose mean age was 40.66 indicating that the caregiver was older than the recipient of care in most instances. This raises great concern because the provision of care places enormous demands on the caregiver whose chances of personal support are extremely limited. This can have a negative impact on the provision of care due to lack of resources. The big question now is, how can these caregivers be expected to provide better care for their mentally ill relatives in the community when the possibility of them securing resources is extremely limited? The persons being cared for also place great demands on the family because they are adults who could be a resource to their families, but instead they are burdens. The family caregivers stated that it was costly for them maintain their relatives in the community. This concern was also raised by Clark (1994) who noted that parents of adults with dual disorders spent far more than those without chronic illnesses ($349 and $154) per month respectively. Most recipients in this study used alcohol, *dagga*. or smoked tobacco. One recipient of care acknowledged this burden he placed on his family and said:

> The lack of employment is a problem. If I can get employed things will be okay. Because if I can get a job I will be able to contribute towards the family and now when you are not working you depend on them. To depend on them you act like a burden, when you request something, they see you like a burden and you really feel you are a burden. If you want to go for a job interview, or you want to do something or have a drink you are afraid to ask because you feel they will think you are too demanding. and when you don't demand, you start to have certain feelings in your heart. You get frustrated and that is the time you become sick.

Several factors have been documented which influenced women to assume caregiving responsibilities. These are often linked to person's availability, closeness and interconnectedness within the family, gender role conditioning and the general life situation (Guberman, et al., 1992). It was found that previous relationships, availability, interconnectedness and closeness influenced caregivers in this sample to assume caregiving roles. The other major factor that played an influential role for caregivers to assume that this responsibility could be attributed to the lack of resources either at community or institutional level in Botswana. Thus, families of the mentally ill had no other alternatives when their relatives were discharged from the hospital but provide care for them.

### Level of Education

Caregivers, especially parents, had comparatively lower educational level than their mentally ill relatives. This could reduce their ability to effectively provide care for their mentally ill relatives because their understanding of mental illness, its treatment, and management could be limited. Mental illness is a very complex phenomenon and it is difficult to understand. The caregivers' low level of education may also pose some difficulties for the nurses translate information easily and appropriately to the caregivers.

### Socio-economic Status

Family caregivers were predominantly from low level income bracket, and most of them were unemployed. They also resided in low income (SHHA) sections of the community. Previous research has indicated the existence of a very strong link between chronic mental illness and low income, unemployment, and area of residence (Mantswe, 1994; Newman, 1994; Warner, 1994). Epidemiological studies on severe mental illness in the U.S. have consistently reported inferior housing conditions among the mentally ill compared to the general population, even in studies such as Newman's (1994) that focused on residentially stable cases.

Poor outcomes in schizophrenia are closely associated with lack of employment and poor provision of basic needs. Warner (1994) argues in the US, deinstitutionalization relies heavily on drugs and has led to the placement of large numbers of the mentally ill in low cost and inadequate settings. He further stated the homeless male schizophrenics were frequently admitted to hospital dirty, sleepless, and floridly psychotic, and after a good night's sleep and some good meals their mental state dramatically improved. These statements underscore the importance of better environments and quality support for the mentally ill in order to successfully integrate them in the community.

The neighborhoods in low income areas are often characterized by high crime rates, high unemployment rates, and high substance abuse, especially alcohol and dagga (Marijuana or Cannabis). The propensity to using these substances is influenced by their easy access and availability. Due to extreme poverty in these neighborhoods, many people eke out an existence by self employment such as brewing and selling of beer. As described earlier, the neighborhoods had many shebeens who brewed and sold beer in their homes to earn a living. All these factors contribute to increased stress and burden on the families of the mentally ill.

The other factor that contributed to easy access to these substances had to do with the socializing process in the Tswana culture. This is characterized by "sharing." A bowl of beer and a puff are passed around and shared within a group as gesture of acceptance or belongingness. This situation exposes the mentally ill persons to access these dangerous substances which adversely affect their quality of life.

Although substance use was also prevalent in the rural area, its magnitude was somewhat low. The substances that were mainly used were alcohol and smoking of *dagga*. Substance use and abuse was found to be a major factor that negatively impacted the health outcomes of the mentally ill in Botswana in this study. The caregivers stated that they observed that when their mentally ill relatives were hospitalized their condition improved, but when they were discharged it deteriorated and they attributed this to drinking of alcohol and smoking of dagga of cannabis. Poor outcomes in schizophrenia with use of substances have been previously reported in the literature (Mantswe, 1994; Newman, 1994; Warner, 1994).

## Psychiatric Morbidity

The diagnosis of recipients in this study was predominantly schizophrenia (97%), thus confirming it as a major psychiatric disorder which tends to become chronic. Chronicity was also confirmed by the duration of care and the length of time the recipient had had the illness. Caregivers in this sample had provided care over an extended period of time (5-26 years). More than 50% of the recipients had had the illness for more than 6 years. In addition, schizophrenia in Botswana ranks first as a cause of psychiatric morbidity as illustrated earlier (see table 1). According to the Mental Health Program Action Plan (1992-97) the number of patients seen with schizophrenia, at outpatient departments and admissions has remained high and constant, ranging between 35.6 - 37% (OPD) and 34 - 35% (admissions). What is not clear, however, is whether these statistics were first visits or included repeated visits and readmissions.

Lack of adherence to treatment advice was found to be higher in the urban sample 76% ($\underline{n}$=13) than the rural one 26% ($\underline{n}$=5). It is not clear what accounts for this. However, it could be attributed to the fact that the rural sample had no other alternatives but to go for check ups because there were no home visits conducted. In contrast to the urban area, where nurses conducted home visits and administered treatment to the patients if they did not go to the clinic for check ups. The visits and administration of medications in the home has advantages and disadvantages. Most importantly, it is ensured that the mentally ill receive their medications. However, this may also render the mentally and their families too dependent on the nurses.

In addition, the families had no reason to encourage their ill relatives to go the clinic for check-ups. Actually, it was more beneficial for the mentally ill not to go for check ups. They saved money and time and they were still be visited by a nurse in their homes. Therefore, lack of adherence to the treatment had some benefits. The mentally ill who went for check ups regularly received no visits from the nurses. Thus it can be argued that the nurses reinforced and rewarded a negative behavior and there was nothing that encouraged the urban families whose ill relatives went for regular check ups to do so as commented one caregiver:

> CG005: He goes for check ups and the nurses don't come here. I have never seen them. Just even to come and check on us and see how we are doing. They don't come. They are not like the ones in South Africa, they used to come and check on me after I had the stroke. I don't mean that they should come every month. At least once every three months would be something. Because they don't visit us if they could at least give us some reading materials about this illness, then I could at least look up some things myself. But there is just nothing.

### Rehospitalization Rates

Rehospitalization rates were found to be very low for the recipients in this sample (18% (n=3) urban and (5% (n=1) rural. The rural sample was found to be doing much better than the urban one considering the fact that the nurses there did not conduct home visits in the rural area. The low rehospitalization rate in the urban sample could be accounted for by the fact that nurses visited the patients in their homes and ensured that they received treatment. Furthermore, the findings of Expressed Emotion (EE) studies, suggest that schizophrenics tend to do better in environments that are less hostile, less provocative, and where their families do not become angry with them (Leffet al., (1990). However, the rehospitalization rates should not be used as criteria to ensure a good quality of life for the mentally ill in the community. The mentally ill in the community still lack very basic resources for minimal survival.

Caregivers in this study demonstrated a very high tolerance limit and acceptance for their relatives. They restrained themselves, exercised self control, and absorbed pain without apparently being angry with their relatives. They cited as qualities of somebody providing care to a mentally ill person as having patience and time for the ill person, tolerance and compromise, ability to give special care, giving them love, careful communication with them, ability to exercise self discipline or self control, and treating the ill person like any other person without marginalizing them.

> CG003: People having this illness are difficult. You have to be patient with them, tolerate them, never argue with them, and exercise a lot of discipline within yourself *(boitshwaro)* because if you don't do that you can harm them. You should also be careful not compete with them and give them love and special care.

The studies that compared the outcome of schizophrenia in rural and urban areas have generally concluded that the rural populations do much better than the urban ones (Warner, 1994). This is often attributed to the rural way of life. However, this area needs further inquiry because rural populations in Botswana are greatly impoverished, thus leading to stressful situations. In this study it was found that the rural sample was more disadvantaged than the urban one due to the gross lack of resources and health and social services.

## History of Mental Illness in the Family

The findings also revealed that at least 30% of the sample had a history of mental illness in the family. In some families there was more than one persons with mental illness. This finding confirms that genetics may play a major role in vulnerability and predispositon to mental illness (Hayes, 1995; Hall, 1996). Different caregiving models for the mentally ill may be required in situations of possibly high risk. Although the caregivers could not describe their relatives' symptoms, they nonetheless could identify that the illness was similar to the one their current relatives were presenting with by saying what it was. They said it was the disease of the head or mind (*Bolwetse ba tlhogo/Bolwetse ba tlhaloganyo).*

## Exploration of Alternative Care

Exploration of alternative care was quite widespread in this sample. Almost all the caregivers reported that they had, at one stage or another, taken their ill relatives to a traditional healer. Although a high number reported to be currently using western health care, there is still a greater preponderance of Batswana using both health care systems. Their health seeking behavior revealed congruence of values and health beliefs that mental illness was caused by witchcraft, disobeying ancestral spirits, and violation of taboos, and traditional healers were the only people capable of curing this illness (Ben-Tovin, 1987).

The caregivers' health seeking behaviors testify that Batswana have not really given up their traditional health practices, although they consult western health care. The complex nature of the illness and its poor prognosis influenced the caregivers to want to understand what the actual problem was about their ill relatives. In their desperation to understand, the caregivers consulted anybody who might offer an explanation.

The utilization of both health care systems has implications for the provision of community mental health care. More importantly, it is necessary to understand the dynamics and interactions between the two systems. The other interesting challenge would be to discover the kind of rewards or satisfaction the caregivers derive from each system. Western health care for the mentally ill in Botswana is free and one would be inclined to think that this should act as an adequate incentive for its utilization. Traditional health care on the other hand is very costly. It would be interesting therefore, to know what motivates the families to utilize it despite its excessive costs.

Traditional healers in Botswana often see illness more from a family or group perspective rather than as an individual problem. Their treatment approaches also target the family or a group. All members of the family have to participate in whatever ritual is performed. The rituals may include sacrifices such as killing a beast and sharing it with the entire clan and neighbors to appease the ancestors. This also attests to the importance of sharing and coming together when there is a problem, thus reaffirming solidarity of a group. Group solidarity in the performance of treatment rituals was also observed in studies conducted in Madgascar, Nigeria, Ethiopia, and Trinidad (Lynton, 1956). Perhaps it might be that this treatment approach appeals more to people who see it as congruent with their belief system.

## Relationship of the Caregiver to the Ill person

Parent caregivers (mothers and fathers ) constituted 60% (n= 18), grandparents 6% (n= 2), daughters to the ill person 13% (n= 4), and spouse 10% (n=3). Others included close relatives such as nieces and sister in law

10% (n= 3). It is evident that parents and daughters are most likely to be more responsible for the care of a mentally ill person in the community. This information is important for health professionals because it can assist them in assessment of the capabilities of a family to assume caregiving responsibility and in the absence of such relatives what necessary preparations would the family require to take on the roles.

## Themes and Concepts from Analysis

Caregivers described their feelings and initial experiences of their relatives' illness as "shocking, painful, sad, sorrow, disbelief, and confusion." They stated that they grieved continuously since the onset of the illness. Some hoped for an eventual recovery, but this did not happen. Thus, the grieving process persisted constantly and continuously. This pain continues because although mental illness does not kill, it confronts families with multiple losses at personal and collective levels. The person is there but is not productive and contributes very little or nothing at all to the family. His or herself lifestyles have changed because of the illness from independence to being very dependent on others. In explaining the grieving process in families with dementia, Kapust (1982), compares the experience with an "ongoing funeral." Noting her observations of the family's struggles, she commented (p. 79):

> Gone is the patient's ability to work and love. Only fragments of familiar behavior and personality remain as sorrowful reminders to the family of what has been lost. The healthy spouse and family experience life as an ongoing funeral; the person they once knew is dying, a little at a time. The family grieves for the losses, yet there are no formalized rituals to help them through this time.

Caring for a mentally ill person does not allow for any closure and acceptance necessary for a healthy resolution of the grieving process. The situation goes on and on. What is more painful about it is that, though being continuous, it is also unpredictable, uncertain, and ever changing. One moment things are okay, and the next moment they have changed to adversity. Atkinson (1994) pointed out that the uncertainty with chronic mental illness creates a situation in which there is no predictable end to the loss nor experience. There is just no opportunity for resolution or closure. Eakes, (1995) labeled this unresolved grief associated with ongoing loss chronic sorrow. The sorrow is chronic because it is constant, endless, and persistent.

Howard's (1994) study which looked at lifelong maternal caregiving for mentally ill children also identified that parents experienced shock, struggle, suffered, endured, persevered, and survived the experience by accepting and coming to terms with the situation. It is important to acknowledge the universal convergence of the effects of caregiving situations of the mentally ill persons on their families.

Despite the difficulties presented by the situation, some caregivers still hoped that their ill relatives would recover. Their hope for recovery was expressed in terms of seeing their ill relatives doing the kinds of things they previously did. They wished to see them return to their former functioning abilities, working, and having relationships.

> CG005: ...I have met a number of cases where they start being wild initially or even uncontrollable, but as time goes on they become better. ...I had expected such things to happen with him.

Hope for recovery acted as a catalyst for the families to continue to search for treatment and alternatives. Hope offsets despair which leads to disorganization, helplessness, and hopelessness. In contrast, hope implies faith, trust, confidence, tenacity, inspiration and encouragement. Hope is futuristic with an inherent will to continue and persist. Lynch (1975) stated that hope is fundamental knowledge that there is a way out of a difficult situation, that things would work out. Hope gives a person a sense of security and that there are solutions to problems.

Hope was shown by the caregivers' endless searching for help to understand this illness and its causes. They tried all types of healers. Even when their ill relatives stabilized, they continued to search for an explanation about this illness. Hope is the opposite of despair, helplessness, and hopelessness. An individual who despairs essentially gives up and one who hopes can transcend a difficult situation because of the inner strength. This quality of hopefulness was particularly apparent when the ill person was younger.

For caregivers of older mentally ill persons, hope for recovery was not an expectation. Although caregivers used expression that symbolized acceptance and willingness to live with a mentally ill person, they in essence had lost hope. The phrase "I have left everything in the hands of the God" could have different interpretations that the families had a mixture of feelings and ambivalence about caregiving. They had lost hope and they had despaired and were helpless. They had lost control of the situation and they had accepted the predicament as it was. Their mentally ill relatives had been ill for a long time and there was nothing that they could imagine anymore to change the situation.

The caregiving situation was perceived as tough, burdensome, and requiring too much responsibility. However, the caregiving roles were still assumed inspite of perceived burden. Caregivers embarked on caregiving because they had to satisfy certain obligations and expectations. Setswana culture deeply values relationships, helping one another, and communal living as opposed to individualism. People also get concerned about what will society think about them rather than what they themselves think.

The caregivers also assumed the caregiving roles irrespective of whether they understood the illness or not. It was a responsibility that could not be relegated to anybody. Assumption of caregiving responsibility embodies a great sense of commitment and sacrifice. Some caregivers sacrificed their jobs and personal support to live with inadequate resources. The sacrifice is also embedded in the relationships, connectedness, and closeness of the family members. This can also be seen as a cohesive force that pulled the family members together. Yamashita (1996) observed that in Japan, family members of a mentally ill person became more cohesive and supportive when one member of the family became ill. Previous literature on caregiving suggested that the elderly married couple consider caring for their impaired spouse as part of the marital contract (Wilson, 1990).

Adult children who cared for their ill parents saw this as an obligation and expectation. The children felt that they were reciprocating their upbringing by caring for their ill parents. Theories on reciprocation posit that there is an inherent indebtedness which constitutes relevant motives and actions; and certain mutual obligations and expectations that each individual fulfills in a given relationship (Brownwell & Shumaker, 1984; Greenberg, 1980). The children of ill parents saw them as Gods (*Badimo*). *Badimo* in the Setswana culture are sacred and should always be obeyed and treated with respect and dignity. The parents on the other hand saw their children as gifts from God and therefore they had to accept the gift that God had given them. They believed that God gave in many ways. This jusitification seemed to sustain and assist the caregivers to accept caregiving responsibilities.

The data indicated that assumption of the caregiving roles commanded a great sense of responsibility and previous relationship between the caregiver and the ill person was a major determinant of the decision to undertake the caregiving role. Both females and males in this sample relinquished or negotiated their personal activities to provide care for their ill relatives. These results differ with from previous findings which suggested that women identified more with caregiving roles and were more likely to relinquish their other activities as compared to their male counterparts (Kessler, 1984). However, it is difficult to draw conclusions on these issues because of the size of the sample. Some caregivers actually left their jobs to assume caregiving roles. This has impacted their personal economic support because they were unable to provide material resources for themselves and their families. This should be taken as a great sacrifice by these people. Some caregivers have alluded to their social and economic status going down after they had a mentally ill person to take care of. Although some mentally ill persons are not physically incapacitated, they could still not be left on their own at home due to their limited competence and poor judgment.

Caregiver demands follow an undulating trajectory. One time things are under control and the next minute they have changed and may be unpleasant. The change can be sudden and unpredictable. Due to the unpredictable nature of the situation, the caregiver were on constant watch and lookout to prevent destruction or what might end up in an explosive situation. The caregivers were perpetually distressed and anguished by the behavior of their relatives. This situation can be taxing to the caregivers. It may drain them emotionally, physically, and materially. This finding is consistent with that of Howard (1994) in which caregivers of the mentally ill found themselves to be constantly struggling, persevering, and in agony.

Some caregivers had actually yielded to the situation because of the lack of control over it. They generally display negative feelings about it. They live in perpetual fear, agony, and worry. They fear for themselves, their ill relatives, and other people because of the unpredictable nature of the situation. In some instances the situation has even exploded.

The caregivers lived with situation on a daily basis and it was amazing how they survived. In some instances the caregivers had to exercise a lot of self-discipline (*boitshwaro)* when dealing with the mentally ill person. They had to learn to tolerate, to communicate better, be patient and accommodating. Developing tolerance, patience, and suppression of feelings can be exhaustive because it is a deliberate effort.

Great concern was expressed regarding the safety of the mentally ill in the community. The community is no longer a safe place for them. They are at risk and vulnerable to the undesirable social habits in the community, especially alcohol, drugs, and rape. This situation does not only present a challenge to the families but to the community based care of the mentally ill as a whole because their diagnosis becomes compounded by these substances. The health outcomes in schizophrenia with alcohol and drug use have been found to be very poor (Newman, 1994; Warner, 1994).

The society in Botswana has changed drastically and these mentally ill persons are predisposed to the danger of being killed or injured especially if they move around at night. Although homelessness of the mentally ill has not become a problem yet in Botswana, it is not that remote.

Caregivers expressed a general dissatisfaction towards formal services. They reported very minimal contact between themselves and health providers. It was found that not all the families were visited, especially those whose ill relatives went for regular check ups. The nurses visited those mentally ill persons who were not taking their medications well and who did not go for regular check ups. It may be concluded that the main objective of the home visits was to administer medications to these mentally ill persons. It was also observed that very little health education took place. In some instances no health education was given at all. Therefore, the objective of the home visits could be seen as an extension of the curative care in the community and not really as an endeavor to educate, support the families, and to involve them as partners in care of their mentally ill relatives. This is an indication that community mental health care has lost its meaning and essence because it is not being implemented they way it was conceptualized. When the community mental health movement was adopted in Botswana, families were to be given optimum support mainly through health educational programs (Ministry of Health Annual Report, 1984). It is evident that this support has not materialized.

Surprisingly, caregivers who were visited in the homes also expressed a lack of involvement in the care of their ill relatives. They stated the nurses spent very brief periods of time with them in the homes and they did not give them any education concerning the illness of their relatives, its treatment, and management. The objectives of home visits and its implementation need to be reexamined in order to accommodate the families.

Primary health care approach embodies partnership and equal participation of the parties involved. The lack of health education and involvement denied the families an opportunity to exercise this responsibility. This lack of partnership in the care at community level defeats the whole purpose for which the primary health services (PHC) have been set out. The essence of PHC is that the individuals should play a central part in their care and should enjoy a partnership relationship with the health providers.

There may be numerous factors that influence this situation: 1) The shortage of community mental health prepared nurses; 2) large catchment areas serviced by these psychiatric clinics; 3) lack of resources, especially transportation for these psychiatric clinics; and 4) capability of nurses to implement PHC; and 5) lack of a clear policy on community mental health care, that is, what it actually falls under, whether it is under local or central government? This lack of clear policy has, to a large extent, contributed to inadequate planning and allocation of resources because neither ministry took responsibility nor accountability. This has greatly stifled the successes of community based care. The lack of resources, especially transportation, was also cited as a major factor that hindered the efficient running of the community mental health services in Botswana (Kgosidintsi, 1990).

The caregivers struggled to provide for the basic needs of their mentally ill relatives. Provision of food, clothing, shelter, and maintenance of good personal cleanliness were the most commonly cited priority needs for the mentally ill persons in this sample. Caregivers stated that their ill relatives ate too much due to the medications they were taking. The lack of adequate provision of food created a major problem for the families who were expected to enforce medications.

Inability of the families to provide for their mentally ill relatives also determines the successes of the community mental health program which relies so much on the families and communities to support their relatives materially. This expectation is ironic in the sense that the data have indicated how impoverished the families were. Most of them were not employed and lived below the poverty line. Even those who got support from other family members still could not meet their needs because the support was insufficient because of too many dependents. Very often, community based care is believed to be less costly and affordable. The results of this study however, have indicated that most families cannot afford to provide adequate care for their mentally ill relatives. It can be concluded that community mental health movement has neither benefited the mentally ill nor their families. Instead it has overburdened them and placed more demands on them. The issue of cost containment needs critical appraisal in order to assist the families in the care of their mentally ill relatives. The notion that community based care is cheap and affordable is fable.

Some caregivers were concerned that their mental ill relatives neglected their personal hygiene. They had to be reminded repeatedly to groom themselves, sometimes without any success. Caregivers of female ill relatives who were still having their menstrual periods were frustrated because they had to act on behalf of their relatives by changing and keeping them clean. This frustrated them especially if they had reached menopause themselves. They stated that their mentally ill relatives often stained their clothes.

Menstruation is something that is not supposed to be seen by other people, especially men, and the mentally ill could not live up to this cultural expectation. This embarrassed and humiliated their families. Jones et al., (1995) reported that caregivers of females suffered less than those of males, but the authors did not state what they were comparing. Contrary to their finding, the caregivers of females in this study reported more suffering than those of males, especially in the area of personal hygiene.

Caregivers talked about the problems inherent in the caregiving situation. They lacked resources at personal, family, and community levels.

The lack of resources greatly impacted the quality of care provided. Most families expressed a great need to provide for their mentally ill relatives. They mentioned that when their ill relatives are hospitalized they are provided with everything. They are dressed well, eat well and are sheltered but when they are discharged, their families could not afford to provide them with this comfort because they do not have the means. Chafetz and Barnes (1989) expressed the same sentiment that once the patients are discharged from the institutions, the "resources do not follow them into the communities." The caregivers reported that the diet that was provided in the mental hospital contradicted the one that they can afford at home. They mentioned that their ill relatives were provided with food stuffs such as cornflakes while admitted in the hospital, but when they were discharged the families could not afford to provide these at home. This discrepancy in the provision of basic commodities has, in some instances created a conflict between the caregivers and their ill relatives because they felt that they were better taken care of in hospital than at home. It is therefore, important to provide commodities that are culturally relevant and available at home in preparation for smooth integration of the mentally ill in the community. The lack of resources has also stifled the successful implementation of the community mental health program in Botswana.

When the community mental health program was initiated, resources were to be made available (Ministry of Health Annual Report, 1984). Unfortunately, this conception has not materialized. The lack of resources in the community has put a lot of strain and demand materially on the caregivers. The problems experienced by the caregivers are also exacerbated by the current escalating poverty in Botswana. From the demographic data of the participants, it was evident that most of them were unemployed and live below the poverty line (PDL). Poverty can adversely affect the implementation of a community mental health program because the community care relies heavily on the families and communities; and if they are poor its successes will be impeded. According to the expenditure and household survey studies in Botswana, about 40-60% households are reported to be living in poverty (Planning for People: A strategy for accelerated human development in Botswana, 1993). With the current escalating rates of unemployment and retrenchment exercises, the situation may have worsened.

Caregiving literature has indicated that families experience a broad array of problems. These include emotional, problems of getting professional help Norbeck et al., 1991), financial resources and so on (Chafetz & Barnes, 1989). The caregivers expressed a need to understand the illness, treatment, and management of their ill relatives. They lacked basic information about mental illness. There is a need to educate the families and give them information about mental illness.

The illness episodes and its unpredictability disrupted the entire household. The caregivers lived for today because it was difficult for them to plan for the future. Many caregivers reported altered household patterns and routines due to having a mentally ill person in the homes. They did not sleep well and could not maintain their household as before.

Since caregiving was seen as a difficult and a very intricate situation, the caregivers described some qualities that they deemed necessary in order to provide care for a mentally ill relative. These qualities were acquired intuitively and vigilantly as they interacted with situation. These qualities were learned through a process of adaptation as the caregivers encountered the situation. Caregivers cited these qualities as being "patient, tolerant, compromising, self disciplined, treating the person in a special way, giving the ill person love and treating them just like anybody without undermining and marginalizing them." These qualities demonstrate that providing care for a mentally ill person requires a deliberate effort in order to accommodate this ill person which can be emotionally exhausting.

The families demonstrated a number of strengths such as ability to problem solve, manage conflicts, and gain resilience. The fact that the families were able to recognize their strengths demonstrated their potential for growth and their determination to survive a difficult situation. The ability to develop strengths also showed the family level of healthy functioning. Health professionals should learn how families cope with the caregiving situation in order to design mental health programs in which the caregivers' needs as well as their assets will be recognized. Research literature pertaining to families of the mentally ill has not explored family strengths. Emphasis found in this literature focused on family burden and hardships that families endure (Baillie et al., 1989; Chafetz & Barnes, 1989; Noberck et al., 1991; Wilson-Skodol, 1989).

The caregivers have also identified several coping strategies e.g., accepting, negotiating and accommodating roles, manipulation through compassionate deceit, and wishing that their ill relative recovered. Some caregivers were able to mobilize resources and turn to other family members for help in order to cope with the situation. Some of these coping strategies stated by the caregivers in this study have also been identified by other researchers such as hope for cure (Fadden, Bebbington, & Kuipers, 1987); managing the client and mobilizing resources (Lefley, 1987; Norbeck et al., 1991), and turning to their family members for help (Chafetz & Barnes, 1989).

The caregiving of the mentally ill in Botswana takes place within a collective or a multiple environment. It is composed of too many caregivers and too many recipients. Collective caregiving is characterized by sharing of responsibilities through cooperating, collaborating, and consultation. Although cooperative and consultative, there is always someone who is considered the key person. This person coordinates the caregiving situation on day to day basis.

In situations where men were also involved in the care, women were responsible for the day to day care and men made major decisions. They considered themselves as providers of material goods such as finances. The main decisions that were made included deciding where to seek help and decisions on hospitalizations. The power and control that males had in these situations fit within the traditional Tswana society hierarchical and decision making structure and is transferred to a caregiving situation. It is important therefore, to take into consideration this structure in the development and implementation of community mental health programs in Botswana.

The multiple caregiving environment offered the family members with an opportunity to take time off, relief or respite because they were able to alternate and fill in for one another. However, this not to suggest that there no problems in multiple caregiving situations.

Extended network systems do not necessarily guarantee optimum support. The presence of many people who could assume caregiving responsibilities can also create problems because other family members may take advantage of others in these situations. This has been sufficiently demonstrated in this because in certain situations, there were some caregivers who assumed caregiving responsibilities voluntarily, while other members of the family showed no interest.

None of the research reviewed on family caregiving of the mentally ill explored the concept of multiple caregiving. Emphasis of this literature focused on individual or primary caregivers. Research information on families has mostly dealt with dyads. In this study there were more people involved in the care and many who benefited from it because of the extended nature of the families in Botswana.

This study has also revealed problems that caregivers experienced. This is an indication that community care can be very difficult if there are no resources to cushion and sustain these caregivers. Warner (1994) argued that community treatment was in fact the antithesis of treatment, resulting in people with psychosis living a life in which even basic needs such as food and shelter were not met. The need for provision of resources in community mental health is critical and urgent for the successful and beneficial development and implementation of programs.

This study has also tried clear some misconceptions and myths arose from western literature that the mentally ill persons seem to have a better outcome in non-industrialized worlds as opposed to industrialized ones, or rural as opposed to urban (Warner, 1994; WHO, 1979)). This study actually indicated that rural sample experienced more hardships than the urban one due the lack of resources. Therefore, the notion that the outcome of schizophrenia is better in the rural and/or less industrialized world remains questionable.

Western literature has also purported that schizophrenia is concentrated in the lower classes in the industrialized world and in the upper castes and classes in the third world (Warner, 1994; WHO, 1979) is also an over simplification. In this study all informants in the urban area came from the low income group (98%). None of the participants in the rural sample was from the upper castes of the society either.

On the whole, the study results converged with some of the findings that were revealed in studies conducted in western countries. This is important because much as research interest is to find how different people are, it should also try to acknowledge similarities in human experiences. Although some of these findings are similar, the development and application of intervention strategies must nonetheless take the specific contexts into consideration. It is believed that application of intervention modalities will differ from context to context depending on the economic, political, social, and cultural factors.

## Summary

Negotiating the caregiving situation is the conceptual framework or theory grounded in the findings of this study. The caregivers had to survive in the midst of all these problems. They achieved this by selecting and utilizing appropriate coping strategies which facilitated this negotiation process. Surviving the experience begins with caregivers' ability to map, establish, and reaffirming the need or existence of a problem or need.

The problems, concerns, and issues inherent in the caregiving situations represent the total caregiving environment. The ill relative is important and matters to his relatives. This nature of their relationships and value placed on the ill person, influences the caregivers to feel responsible to fulfill certain obligations and cultural expectations.

The caregivers have many and different situations to contend with. This was demonstrated earlier by the rearrangements and adjustments that they had to be done when caregiving responsibilities were assumed e.g., relinquishing of personal and social activities, leaving a job, adjusting work schedules to accommodate the caregiving roles. All these were done in an attempt to negotiate the caregiving situation.

Negotiating refers to making arrangements, adjustments, and striving towards settling of issues in a situation. It may also mean accommodating the persons needs and realigning them together to avoid conflicts. It has a notion of personal commitment, sacrifice, compromise and tolerance.

In negotiating the caregiving situation, the caregivers utilized different coping strategies. They often times selected what worked for them in their particular situations. This was because caregiving situations were not equivalent. They had many variations in caregiver demands. These included situational demands such as the status of the condition of the sick person, severity of illness, response to medications, functional abilities, and reactions and responses of family members to the situation. These variations shaped the way family caregivers dealt with their own specific situations facing them. More importantly, the caregivers' personal background and experience, meanings, and beliefs set up certain possibilities for the kinds of care they provided.

Caregivers' background, meanings, history, experiences, perceptions, understanding of the illness, concerns, and demands comprised their "social worlds." Their coping and the negotiated caregiving situation is set up by these "social worlds." These "social worlds" are complex and unique to the people experiencing them. Hence the selection and application of coping strategies depended on how the caregivers perceived their effectiveness in dealing with the situation.

Prescription of coping strategies is difficult and present a challenge to health workers. They have to learn coping strategies employed by the caregivers and this may open up the possibility for understanding the meanings and concerns that guide care from the caregivers' perspectives. This can hopefully drive the development of appropriate and relevant intervention strategies.

The experiences that the families of the mentally ill persons in the community encountered have great implications in the implementation of community mental health services in Botswana. The following chapter discusses such implications. Suggestions of how community mental health care in Botswana can be improved in order to benefit the individual patients, their families and communities at large are proposed.

# CHAPTER SIX: CONCLUSION, IMPLICATIONS AND LIMITATIONS

## Conclusion

This chapter presents a summary of the study. Its strengths and limitations will also be discussed. In addition, implications for mental health nursing practice, education of mental health professionals, research on mental health issues, and policy related to mental health in Botswana will be discussed. A qualitative grounded theory design was done. Constant comparative data analysis techniques of grounded theory were utilized to analyze the data.

The study took place in Botswana. Two areas were selected, an urban (Gaborone) and a rural (Molepolole). The goal here was to compare whether rural and urban caregivers differentially experienced caregiving situation. The rural sample compared quite favorably with the urban sample. In some instances it even did better than the urban area considering the disparities in the availability of resources in the two areas. The number of ill persons falling off treatment was low in the rural area (26%) as compared to the urban area (76%). Rehospitalization rates were also low in the rural area (5%) as compared to the urban area (18%). Also, the caregivers in the rural area ensured that their relatives went for check ups and took their medications. They had no other alternative because there were no home visits conducted.

A convenience sample of thirty (N= 30) female and male caregivers (n=16 urban and n= 14 rural) was selected to conduct in-depth interviews to investigate caregiving experiences, demands, and social support. In addition, four family group interviews were also conducted to explore the concept of multiple caregiving prevalent in Tswana culture. The main purpose of the group interviews was to elicit information on how the family members shared responsibilities, especially as regards gender roles.

In-depth interviews revealed that caregivers experienced a myriad of problems and hardships in providing care for their mentally ill relatives at home. The problems related to their first responses and reaction to their relatives' illness. Caregivers described their responses as characterize by a persistent and continuous grieving process. They grieved for their ill relatives. The terms they used to described their experiences were shock, disbelief, sorrow, sadness, anguish, suffering, agony. The caregivers stated that they are always lamenting to see their relatives in that situation.

In this initial state, they realized that there was a problem which needed attention. In addressing the problem they searched for help. The help they searched for was influenced by the beliefs that they held about the causes of mental illness. Usually traditional healers would be consulted because of the believe that mental illness was due to witchcraft, disobeying ancestors or violating a taboo or punishment from God in which case family ritual will be performed to appease the spirits. Simultaneous help is also sought from western health care. However, the caregivers tried anything that they thought might help. Searching for anything that might help their relative was influenced by their sense of hope that their ill relative will recovery. Hope that their loved ones will recover and revert to their previous lifestyles and functional abilities.

Caregivers gave their own perception of mental illness and its causes. They perceived mental illness to be a unidimensional entity with a multidimensional causology. They said it was the disease of the head or the mind and it could result from witchcraft, disobeying ancestors, violating a taboo, or as a punishment from God(s). Other causes could be stress, trauma, aging, and loss of an object such as losing a child.

The caregiving situation was believed to be difficult, hard, tough, and burdensome because of the lack of resources at personal, family, and community level. Caregivers expressed a need for information about mental illness, its causes, treatment, and management. They felt totally inadequate to care for their ill relatives. They also lacked control of the situation because they could not control their relatives who just idled in the community with nothing to do. They called for resources at community level such as rehabilitation and vocational centers to provide their ill relative with structured environments which will occupy them and reduce the idling behavior. This could perhaps take them away from the bad environmental influence.

The day to day care of the mentally ill person centered around provision of basic needs, e.g., food, shelter, and clothing, attention to personal grooming, and supervision of medications. Caregivers expressed their inability to provide ill relatives with basic commodities such as food and clothing.

Caregivers also stated how they felt about the caregiving itself, feelings about the ill persons, formal services and the community. They felt alone and left out in the care because the health professionals did not involve them in their relatives' care.

They enumerated qualities they considered important in the care of mentally ill persons in the community. They said that one has to be tolerant, have patience, time for the ill person, have the ability to love, to treat them with respect, to communicate with them, and the ability to improve relationships and maintain them. Most significant, caregivers stated that exercising a lot of control, self discipline, suppressing their feelings and absorbing pain without being angry as of paramount importance in the care of the mentally ill. These qualities require a deliberate effort and time to develop.

Caregivers used selected coping strategies that enabled them to deal with the caregiving situation. The strategies included accepting, negotiating, accommodating, and manipulation through compassionate deceit. Although some of these coping strategies may actually infantilize the ill persons, they assisted the caregivers to achieve control of the situation and continue caregiving. These strategies were considered dynamic because they were not always effective. What worked in one situation may not necessarily work in another. Although these strategies were employed by the caregivers to survive the daily situation, they were mostly done with the intent of improving the well being of the ill person.

The multiple caregiving situation consisted of two distinct dichotomous groups with many people giving care and many receiving it. Multiple caregiving situations were composed of many different people with different diverse health needs. These included some of the caregivers themselves who depended on somebody for support, the ill persons, the children, and elderly people who composed the family or caregiving environment.

A model that described the complex nature and the intricacy of the caregiving situation was proposed in the image of a spider web. The spider web metaphor indicated the entangling and difficult nature of the caregiving situation. The web basically mapped out the caregiving situation. It may increase in size due to the increasing problems of the caregiver or may decrease due to available assistance and resources available. The untidiness of the web indicated the unpredictable, uncertain, and the turbulent nature of the caregiving situation which was dictated by the ill person's condition. The negotiation model showed how the family caregivers deciphered resources, interactions, and relationships and employed strategies of coping to negotiate and manage the caregiving situation more effectively.

## Contributions of the Study

A number of strengths were identified in this study. The data collection consisted of in-depth interviews and informants shared stories about their experiences of caregiving from their own perspective. From that point of view, this research has been a human interaction. The study revealed caregivers' struggles, pains, agonies, difficulties, problems, and concerns about the caregiving of mentally ill persons in the community. The knowledge base generated calls for culturally, socially, economically, and politically appropriate interventions and programs to address the needs of families of the mentally ill. Most caregivers also expressed intense need for material resources.

The most significant strength of this study is that it examined subjective experiences of the families of the mentally ill in a caregiving situation through their own voices. The study also explicated the concept of multiple caregiving. Although families have been studied but they have never been looked at from a collective caregiving perspective. The study has also explored the qualities and strengths of the caregivers to the mentally ill in the community. Most previous studies have concentrated on the negative impact of the caregiving situation and problems and hardships encountered in caregiving and never looked at the positive side of caregiving (Baillie et al., 1989; Chafetz & Barnes, 1989; Francel et al., 1987; Kgosidintsi, 1990; Mogorosi, 1994; Mantswe, 1994; Norbeck, et al., 1991). Exploring and recognizing positive living and the strengths of the families can serve as a springboard for the development of intervention strategies based on caregivers' experiences.

This study also identified some problems and discrepancies inherent in the delivery of community mental care in Botswana. Most significant are the objectives of the community mental health program and the role of CMH nurses. It was identified that the CMH nurses merely administer medications to the ill persons with very little or no family contact and education. It is imperative to understand the what could be contributing to this. The study also raised a need that the caregiving situation cannot be understood without understanding every piece of the puzzle, such as the health professionals, the client, community, policy concerning mental health care and the social welfare programs operative in Botswana. These areas are quite intertwined and they greatly impact on one another.

The study sample was mainly drawn from low income areas. Although this might be seen as a limitation, it is on the other hand a strength, because these people were the most needy and if the needs of caregivers must be understood, then people who are most affected should be included in the samples. The participants also used this opportunity to share with me their caregiving situation which allowed and was helpful for them to ventilate their feelings.

## Implications for the Study

### Implications for Mental Health Nursing

Community based care for the mentally ill in Botswana requires a reorientation, especially from the health provider perspective. What is currently being done is not community based care but rather curative care extended to a community setting. The nurses visit patients in the homes mainly to administer medications. This study confirms findings from Kgosidintsi (1990) which also examined the role of the community mental health nurse.

Interventions that community mental health nurses employ should not encourage dependency on the system, but rather should strive to render the families and their mentally ill persons more independent and responsible. The current practice of visiting the mentally ill who have dropped out of treatment needs to be reconsidered. As already mentioned this seems to reward a negative behavior t(hat if one does not go for check ups, the nurses will visit). Programs that attract ill persons and their families to come for check ups should be developed. Such programs should build in incentives that will encourage the mentally ill to go for check ups. This calls for resources and innovations in the implementation of community mental health programs.

It was evident in the study that families and their relatives use traditional healers. Mental health nurses should find ways to work collaboratively with these traditional healers because some take the ill person off western treatment and often times this leads to relapses. A way that in which both treatment can be used simultaneously should be found. Traditional healers also should made aware that they can refer the mentally ill to western care if they cannot understand the illness. Some traditional healers have acknowledged their inability to cure mental disorders, especially when the patients are actively psychotic. Therefore, they have sought collaboration with the western health care providers to refer these patients to them (Mdluli & Msomi (1989).

There are no community programs in health education about the illness, nor programs that assist and prepare the families to assume the caregiving roles and also to cope with mental illness. There are no programs in place that teach individuals and families to prevent mental illness. Although mental illness cannot be cured, there are some disturbances that can be prevented such as substance abuse and depression due stress.

Substance use and abuse was found to be a major factor that exacerbates mental illness. These substances are readily available in the communities. The community needs to be educated about the danger of these substances. Although there are laws which prohibit the possession and use of these substances, they are not enforced adequately. More stringent law enforcement programs need to employed. Strict control not to expose children under age to these substances should also be done.

More family involvement, participation and partnerships are needed. Health workers need to find ways to involve the families in the care of their ill relatives. For example, family assessments should be done before a mentally ill person is discharged from a mental hospital. This will ascertain the family's ability to care for such a person.

More vigorous educational programs need to be developed and information about mental illness disseminated. Health providers should spend more time with the family caregivers and offer them professional support. Norbeck et al., (1991) found that families of the mentally ill reported the least support from health professionals. Nurses must be more visible to the families than they are now. The community mental health services should be seen as an opportunity for mental health nurses to intervene and mitigate a number of dysfunctional patterns evident among family caregivers of the mentally ill.

It is evident from the data that there is very little or no intervention to assist the families to cope with mental illness. Development of strategies to assist these families is critical and urgent. However, the staffing situation of the community mental health nurses is grossly inadequate. The country needs to prepare more mental health nurses not only to work in the psychiatric clinics but also in the general clinics. The Mental health action plan (Ministry of Health Botswana 1992-1997) suggested that mental health services be regarded as an integral part of the general health system. Compounding the situation further is the fact that the catchment areas serviced by the psychiatric clinics are very big and, with lack of resources, the nurses cannot be expected to execute their duties efficiently.

## Implications for Mental Health Nursing Curriculum

The curriculum of nursing too needs to reflect the current proposed philosophy where every nurse can be able carry out mental health work. The education of nurses must also prepare them for community settings rather than institutional practice. The primary health care strategy (PHC), which emphasizes the families and communities as the focal points in care has long been adopted in the country. However, nursing curriculum has not been reoriented to embrace this philosophy of care. If attempts have been made to base nursing curriculum on PHC, nurses have failed to implement it in real practice. If community mental health is to succeed, nursing education needs to respond to the real needs and challenges of individuals, families and communities.

The community health nurses also need frequent upgrading of their skills and competencies in community mental health work. This will ensure that they keep abreast with current developments in their area of practice.

## Implications for Theory

The experiences expressed by the caregivers and problems they encountered suggest a need for development of theory or knowledge base regarding the care of the mentally ill in Botswana. Lack of involvement of the families and communities in the care of their mentally ill relatives does not only frustrate the families but contributes to poor quality health outcomes of the mentally ill populations in the communities. Ways of how ill persons, families, communities, and mental health professional ca work together need to be found and this can only be achieved by a sound knowledge base in community mental health care.

This study has attempted to draw a conceptualization of the caregiving situation in Botswana through a negotiation model. This conceptual representation needs further development so that the whole caregiving situation of the mentally ill in Botswana is understood. The caregiving situation is broad and complex. It includes the families, the mentally ill, the health services, both western and traditional, political economic, and cultural factors.

## Implications for Research

The caregiving situations of the mentally ill need further study. Caregiving of the mentally ill in the community is intricate with many interacting variables. The problems surrounding this phenomenon keep on increasing and are dynamic. They need to be fully investigated and understood. The caregiving situation should be studied from several perspectives, vis mentally ill person's perspective, health provider perspective, family's perspective, community's perspective, and lastly from a policy point of view. When data from all these areas are put together, then the caregiving phenomenon can be discerned. It is this complete tapestry or puzzle that can enable the development of relevant and appropriate intervention strategies for the care for the care of the mentally ill in the community. A collaborative research model is for understanding the caregiving situation of the mentally ill in the community is proposed (see figure 5).

Research should also begin to acknowledge the strengths that families have and explore these positive aspects in order to utilize these assets. These can assist in the development of relevant and appropriate programs and interventions.

## Implication for Policy Development

The health care system in Botswana is administered by two Ministries, the Ministry of Health (MOH) which forms the central government and the Ministry of Local Government and Lands (MLGL) which is composed of the local authorities and clinics. Presumably all types of community based care should fall under the latter. However, the psychiatric outpatients clinics are attached to district hospitals and the nurses belong to Ministry of health or central government. Although health is a responsibility of MOH, most clinics fall under MLGL. Therefore, in essence, MLGL should be responsible for all community based care. This confusion has made it very difficult to provide resources for the community mental health services because none of the two structures took responsibility. Central government thought it was the responsibility of Local authorities and vice versa. A clear and well articulated policy on community based care is needed.

Provision of resources is a major concern in community mental health care because its successes depend largely on their availability and utilization. Communities in Botswana lack resources. There are no recreational nor vocational facilities for the mentally ill. To expect the communities to provide their own resources would be would be very unrealistic because most of the families live in poverty. Survey studies on income and expenditure indicated that households living below poverty line (PDL), range between 45% and 64% (Planning for people: A strategy for accelerated human development in Botswana, 1993). With recent escalation on unemployment rates and country-wide retrenchments, it is envisaged that the situation will get worse. This current state of affairs demands economic reforms and social welfare policy to alleviate poverty. These economic reforms should cover physical and mental disability and those who are unemployed if a better quality life is to be attained.

In Botswana there are social welfare provisions for supplementary food rations for various groups. These include the under five, pregnant mothers, and destitutes. Recently an old age pension scheme has been implemented. The destitute scheme was designed for the poor who were unable to provide for their basic needs and had nobody to provide for them. These schemes however, have not benefited the mentally ill. Therefore, Botswana needs to develop a comprehensive and harmonious policy on social welfare and social security. The various elements of social policy that currently exist are neither related nor well coordinated. The aim of such a policy should provide a safety net for the carefully selected and targeted groups of the needy (Mugabe, 1996. Unpublished paper). The lack of well articulated policy on social welfare and social security has greatly disadvantaged the mentally ill population because they did not fit any category of the vulnerable groups. It is believed that this policy would be oriented towards fostering growth and development with more emphasis rehabilitation rather than creating dependency.

## Limitations

It should be noted that these research findings are preliminary and somewhat restricted in scope due to the convenience of the sample and how it was drawn. The sample was drawn mainly from clinical practice areas and thus excludes caregivers who do not utilize these facilities. Nevertheless, the findings have numerous implications for community mental health care.

The implications will be discussed in terms of clinical nursing practice, research and policy development as regards the care and social welfare of the mentally ill in the community in general.

The interviews were a snapshot rather than repeated. Capturing experiences of caregiving as they were interpreted and reported by informants at one point in time for a single audience may limit the study. There were many stories that were told but the investigator chose to tell the stories she wished to tell and this constitutes partial truths. Although the active voices of the informants constructed the report, the excerpts were also chosen by the researcher.

## Recommendations

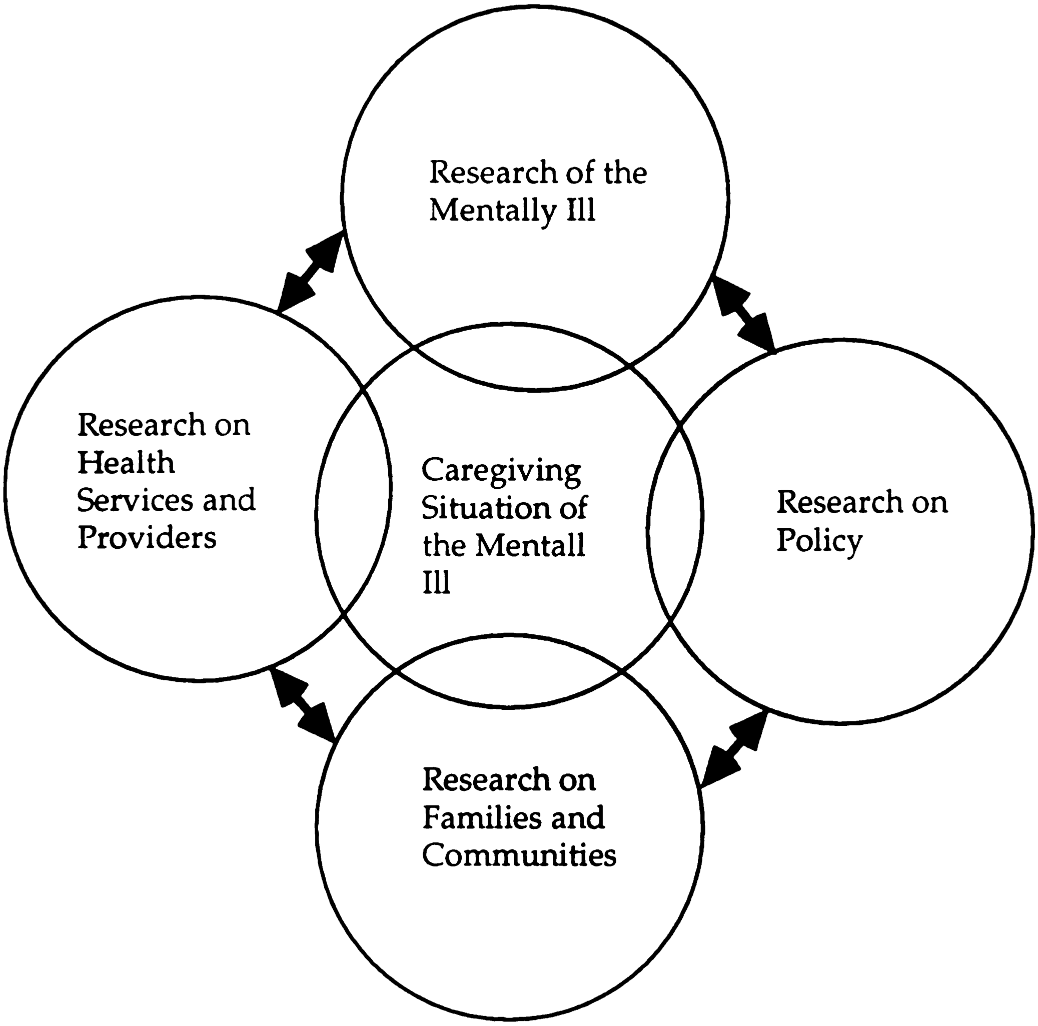
Support to the support systems emerged as critical for the successful integration of the mentally ill in the community in Botswana. The following are recommendations of how support for the families can be secured.

- Need to support the families materially with food and clothing for their mentally ill relatives. Therefore, rations should be extended to the mentally ill population.
- Social welfare must be developed for the mentally ill disabled individual to ensure their quality of life in the community.
- Families and their mentally ill relatives should be trained in the development of craft skills to render them economically independent.
- Design and development of community programs such as rehabilitation and vocational
- Collaboration and integration of care of the mentally ill in all spheres of the community such as churches, schools, traditional healers, traditional social structures (e.g., kgotlas). This will ensure involvement of

community leaders in the prevention and care of the mentally ill in the community.

- Existing community models in Botswana that have been developed to target the disadvantaged populations should be emulated and adopted for possible provision of basic commodities for the mentally ill in Botswana. These include the programs for the vulnerable groups such as maternal and child, projects such as "helping the poor help themselves" which targets the urban and rural poor developed by the Nurses Association of Botswana.
- Lastly, a comprehensive mental health policy in Botswana needs to be developed.

Figure: 5 A proposed Collaborative Research Model in Community Mental Health in Botswana



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# APPENDIX A: Demographic Profile For Caregivers

Place of residence:

Tribe: Age: Sex:

Marital Status: Religion:

Educational Level:

- Primary:
- Secondary:
- Post Secondary:
- University:

Occupation: Income:

Other Sources of Income:

Sources of Support: Financial

Material

Emotional

Relationship to the ill person

Duration of care: No. of careers:

Size of the family: Composition:

Who visits: How often:

Who Makes decisions about care:

Relationship to ill person:

History of mental illness in the family:

Type of health care used:

Type of health care preferred:

# APPENDIX B Demographic Profile for Care Recipients

Place of residence:

Tribe: Age: Sex:

Marital Status: Religion:

Educational Level:

Primary:

Secondary:

Post Secondary:

University:

Occupation: Income:

Other Sources of Income:

Sources of Support: Financial

Material

Emotional

Previous work history

Duration of illness: Diagnosis:

Readmission Rate:

Compliance with treatment:

History of mental illness in the family:

Type of health care used:

Type of health care preferred:

# APPENDIX C: Individual Interview Guide

1. How long have you been taking care of your relative?

2. Can you tell me how it was like the first time you took care of your relative?

3. How is it now?

4. Describe to me the care you give to your relative?

Think about the care you have been giving to your mentally ill relative and describe to me your experiences

5. What have been your greatest demands?

6. What have been your greatest concerns?

7. What has been the hardest thing about giving care to your relative?

8. What was most gratifying about the care?

9. What do you consider to be the most important things about caring for your relative?

10. What advice or suggestions would you give to someone who has assume this responsibility?

11. Tell me what your life was like before you took care of your relative

12. What is your life like now?

13. Who have helped you most in the care of your ill relative?

14. What did this person do to help you?

15. What kind of things such as support resources are available to you and who provides them?

16. What factors have facilitated or hindered support?

Probes

a). What kind of things contributed to great support?

# APPENDIX D: Family Group Interview Guide

1. Think about the care you have been giving to your mentally ill relative and describe to me your experiences

2. What have been your greatest demands?

3. What have been your greatest concerns and worries?

4. What has been the hardest thing about giving care to your relative?

5. What was most gratifying about the care?

6. What do you consider to be the most important things about caring for your relative?

7. What advice or suggestions would you give to someone who has assume this responsibility?

8. Tell me what your life was like before you took care of your relative

9. What is your life like now?

10. Who have helped you most in the care of your ill relative?

11. What did this person do to help you?

12. What kind of things such as support resources are available to you and who provides them?

13. What factors have facilitated or hindered support?

Probes

a). What kind of things contributed to great support?

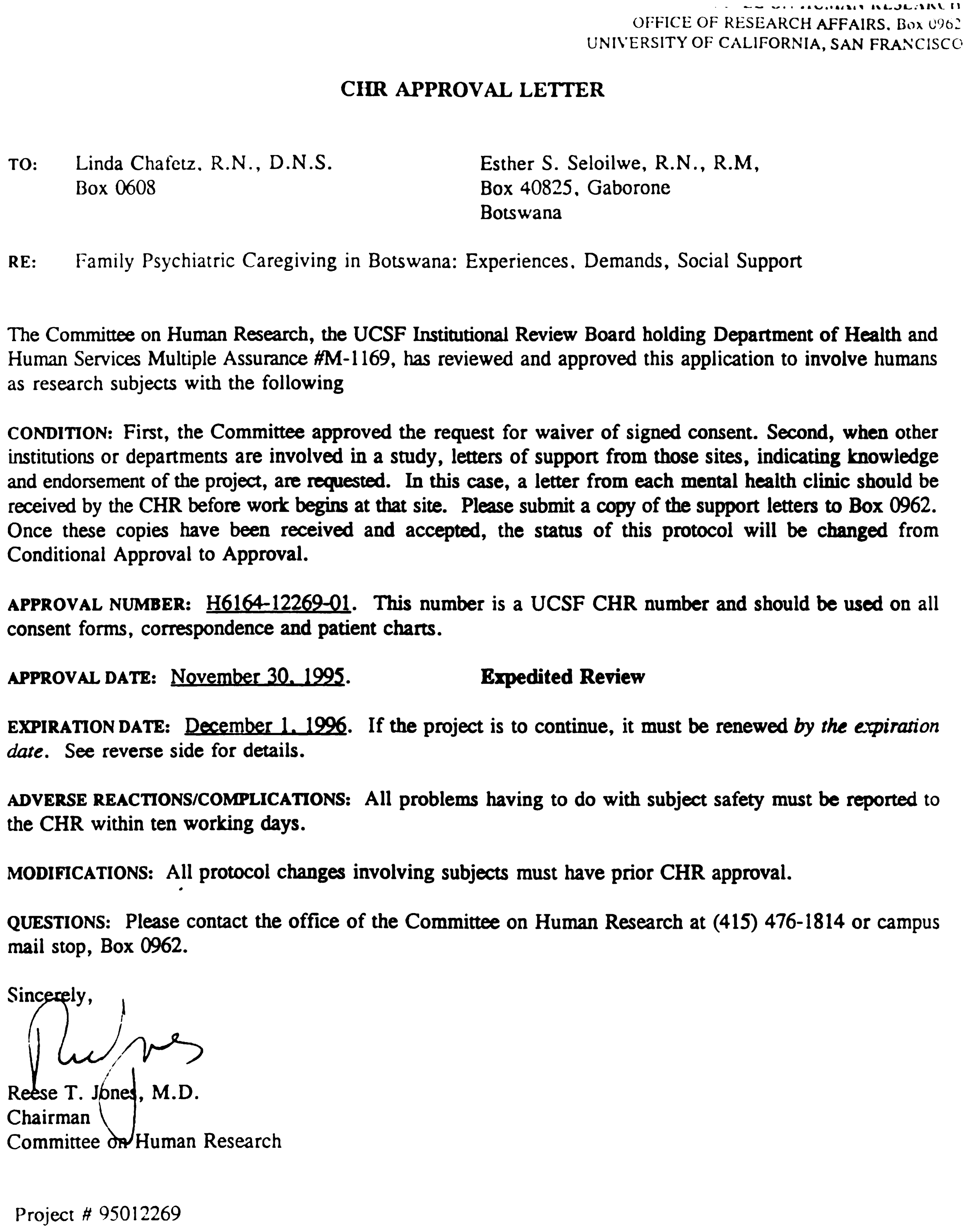
b). What kind of things hindered support? Why?

c). What kind of support do you think families of the mentally ill relatives in the home need?

d). Who should provide this support?

e). Who has given you the greatest support in the care of your mentally ill relative?

# APPENDIX E: CHR Approval



OFFICE OF RESEARCH AFFAIRS, Box 0962
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

**CHR APPROVAL LETTER**

TO: Linda Chafetz, R.N., D.N.S.
Box 0608

Esther S. Seloilwe, R.N., R.M,
Box 40825, Gaborone
Botswana

RE: Family Psychiatric Caregiving in Botswana: Experiences, Demands, Social Support

The Committee on Human Research, the UCSF Institutional Review Board holding Department of Health and Human Services Multiple Assurance #M-1169, has reviewed and approved this application to involve humans as research subjects with the following

CONDITION: First, the Committee approved the request for waiver of signed consent. Second, when other institutions or departments are involved in a study, letters of support from those sites, indicating knowledge and endorsement of the project, are requested. In this case, a letter from each mental health clinic should be received by the CHR before work begins at that site. Please submit a copy of the support letters to Box 0962. Once these copies have been received and accepted, the status of this protocol will be changed from Conditional Approval to Approval.

APPROVAL NUMBER: H6164-12269-01. This number is a UCSF CHR number and should be used on all consent forms, correspondence and patient charts.

APPROVAL DATE: November 30, 1995. **Expedited Review**

EXPIRATION DATE: December 1, 1996. If the project is to continue, it must be renewed *by the expiration date*. See reverse side for details.

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within ten working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0962.

Sincerely,

Reese T. Jones, M.D.
Chairman
Committee on Human Research

Project # 95012269

P.O. Box 40825
Gaborone
Botswana
FAX: 011-267-356591

October 16, 1995

TO: Committee on Human research
University of California, San Francisco
Suite 11, Laurel Heights Campus
Box 0962
San Francisco, CA 94143-0962

FROM: Esther Seloilwe, R.N., M.S.

RE: "Family Psychiatric Caregiving in Botswana: Experiences, Demands, and Social Support"

I am submitting an application for review of this project which constitutes my doctoral dissertation research. I plan to conduct the study in Botswana, where I successfully collected pilot data for this project in 1994 (CHR # H6577-10632-01). I am leaving for Botswana at the end of the month. At my arrival, I will begin the process of gaining access to research participants through mental health clinics. This will involve contacting family members who accompany the mentally ill relative to clinic visits. It may also involve contacting families referred to me by clinic staff.

I will receive onsite supervision and guidance from Dr. Naomi Seboni, who is an expert in field research methods and an external member of my Dissertation Committee. Dr. Seboni is a nurse educator holding an appointment at the University of Botswana. She received her Ph.D. from the UCSF School of Nursing in 1993.

Also, be informed that this project will be submitted for further review by the Office of the President in Botswana, to monitor sensitivity to specific cultural and ethical issues.

Finally, I am an experienced psychiatric nurse and, as noted above, I have conducted prior research with similar families in Botswana, with CHR approval.

I believe that my experience and the safeguards that I have described in Botswana should assure protection of human subjects in this research. If there are any problems or questions, I will be in continuous contact by E-mail with my dissertation committee chairperson, Dr. Linda Chafetz. She may be reached at UCSF, N511K, Box 0608, telephone number 476-2726. I look forward to hearing from you.

Yours Sincerely,

Esther Seloilwe, R.N., M.S.

ES/lc

# COMMITTEE ON HUMAN RESEARCH
# INITIAL SUBCOMMITTEE REVIEW APPLICATION
# COVER PAGE

**PRINCIPAL INVESTIGATOR** (UCSF Faculty) (Name & Degree) Linda Chafetz, DNS
**University Title** Associate Professor
**Dept.** CMHAN, Nursing
**Mailing Address** (Campus) N511K, Box 0608
**Phone Number** 41 5-476-2726
**Is P.I. Sponsor/Advisor Only?** Yes
**CO-P.I.** (Name & Degree) Esther S. Seloilwe
**Title** Doctoral Candidate
**University Dept.** CMHAN, Nursing
**Mailing Address** (Campus) Box 40825, Gaborone, Botswana
**Phone Number** 011-267-351836
**SUBMISSION DATE** October, 1995
**PROJECT TITLE** (Up to 150 Spaces) Family Psychiatric caregiving in Botswana: Experiences, demands, social suppor

**EXPEDITED REVIEW CATEGORY NUMBER** 11 (from PART V-B of the *UCSF Guidelines for Research Involving Human Subjects*, October 1987)

**NAMES/DEGREES OF ALL OTHER INVESTIGATORS:**

**HISTORY OF THIS PROJECT:**
**Previous CHR approval #**
☒ **New**
☐ **Modification** (Highlight changes in protocol.)
☐ **Renewal** (Expiration Date )

**PROCEDURES** (List all procedures to be done for purposes of the study, including surveys, chart reviews, etc.):

Interviews, field observations, and group ~~and~~ family interviews

PRINCIPAL INVESTIGATOR'S SIGNATURE & DATE

**SITE** (Check and discuss in protocol):
☐ **Parnassus** ☐ **VAMC** ☐ **SFGH** ☐ **MtZION**
☐ **Other UCSF site** ☒ **Foreign** Botswana
**Other**

**SUBJECTS** (Discuss in protocol.)
**Estimate total number of subjects at all sites checked above.**
**(If multicenter, discuss overall number of subjects in protocol.)**
**Number** (This Year) (Total for Study)
**Source(s)**
**Reimbursement**

**Special Subject Populations:** (Check and discuss in protocol. See Appendix G of *CHR Guidelines*.)
☐ HIV-Infected Individuals
☐ Minors
☐ Fetuses, Pregnant Women
☐ Those Unable to Speak or Read English
☐ Those Unable to Consent for Themselves
☐ Prisoners

**FUNDING:**
Will this study be funded?
☐ Yes ☐ No ☐ Pending
☐ Federal Gov. ☐ Other Gov. (i.e., State, City, WHO)
☐ Pharmaceutical/Device Co. ☒ Other Private
☐ Campus & University-wide Programs
☐ Departmental
Agency/Sponsor Name (Grant/Contract #, if known):

(See reverse side for instructions and format.)

COMMITTEE ON HUMAN RESEARCH SHORT FORM APPLICATION PROTOCOL

PRINCIPAL INVESTIGATOR (UCSF Faculty)
(Name & degree) Linda Chafetz, DNS

University Title
Associate Professor

Mailing Address
(Campus) Box 0694

Phone 476-2726

Is P. I. Sponsor/
Advisor Only? Yes

CO-PI
(Name & degree) Esther Seloilwe, MS

University Title
Doctoral candidate

Dept. Community Mental Health & Administrative Nursing

Mailing Address
Box 40825 Gaborone
Botswana

Phone
267-351836
Fax: 267-356591

Submission Date: October, 1995

Project Title: Family Psychiatric caregiving in Botswana: Experiences, demands, and social support.

1. STUDY AIM, BACKGROUND, AND DESIGN

This qualitative descriptive study on family psychiatric caregiving in Botswana will explore: the experiences of caregivers for the mentally ill at home from their own perspective; the types of available support and resources that promote coping with the caregiving situation. It will also explore how caregiver needs and demands have been met by the existing health care delivery system and by the available informal support networks. The study is based on the social support research that indicates that support resources can dramatically influence the ways the family members cope with their problems and can change their attitudes and perspectives about mental illness. Interviews will be conducted with the individual family caregivers and selected family groups to understand the impact and the roles of multiple participants on a psychiatric caregiving situation. Field observations will explicate the interactive processes in a family caregiving situation.

2. SUBJECT POPULATION: INCLUSION/EXCLUSION CRITERIA, USE OF SUBJECT GROUPS, AND METHODS OF ACCESS.

Family caregivers for the mentally ill in the home environment in Botswana are the target population. Family caregivers are defined as anybody who lives with a mentally ill person in the home and participates in the care of this person. Family caregivers will be recruited through mental health clinics when the family caregivers accompany their relatives for checkups. In addition, unaccompanied clients at these clinics will be asked to identify the persons who are responsible for their care who may then be asked to participate in the study. Participation in group interviews will be sought from the head of the family and the other family members. Lastly, the clinic staff may refer family members who are interested in participating in the study. Once potential participants have been identified, they will be asked individually and privately to participate in the study. The total number of participants required for the study is thirty.

## 3. PROCEDURES TO BE DONE FOR THE PURPOSES OF THE STUDY

This study will use field observations, group interviews, and semi-structured individual interviews to collect data (see attached interview guide appendix C). Field observations will be done concurrently with the interviews. The interviews will last approximately two hours. Tape recording and note taking will only be done with permission of the participants. The participants will be informed that they reserve the right to refuse tape recording and note taking during the course of the interview.

## 4. RISKS: POTENTIAL RISKS/DISCOMFORTS TO SUBJECTS, INCLUDING POSSIBLE LOSS OF CONFIDENTIALITY AND METHODS OF MINIMIZING THESE RISKS.

The potential risks for the informants include loss of confidentiality and privacy. There may also be some discomfort because some questions may bring back painful memories. To protect confidentiality the data will be kept anonymous. Data sets will be identified by codes only. The interview transcripts and field notes will also be identified by numbers and will bear no names. This will ensure that data cannot be related to any particular person. To minimize loss of privacy, the interviews will be conducted in informants' home or wherever the informant feels most comfortable and safe. Participants will also be told and reminded that they can stop the interview, choose not answer any particular questions, or can withdraw from the study at any time. In addition, by virtue of my preparation as psychiatric nurse with experience in the field, I will strive to minimize harm and protect the participants as much as possible.

## 5. BENEFITS: POTENTIAL DIRECT BENEFITS TO SUBJECTS AND BENEFITS TO THE SUBJECT GROUP, MEDICAL SCIENCE AND/OR SOCIETY

This study has no direct or potential benefits to the informants. However, sharing their practical experiences about their caregiving situations for their mentally ill relatives may benefit other people in the same situation. The results of the study will be compiled and shared with potential family caregivers and health professionals who work with families with chronic mental illness in the home. This information may assist mental health professionals to develop relevant interventions that can assist the families to better cope with mental illness in the home or community.

## 6. CONSENT PROCESS AND DOCUMENTATION

Verbal consent to participate in this study will be sought as this is the usual method in Botswana. Participants will be given an information sheet which will further ensure their privacy, because nothing will be signed that can be traced to them (see attached information sheet appendix B). Signed consent is not a usual procedure in Botswana and people can be distrustful and suspicious if asked to sign a form. Those willing to participate will be given written information about the study if they are able to read (its purpose, aims, and risks). If the participants cannot read, the purposes, aims, and risks of the study will be explained to them. The informants will be given the opportunity to ask any questions they may have about the study.

## 7. QUALIFICATIONS OF INVESTIGATORS

Linda Chafetz, R.N., DNS is Associate Professor in the Department of Community Mental Health and Administrative Nursing in the School of Nursing, University of California, San Francisco.
Esther Seloilwe R.N., Msc., is a doctoral candidate in the Department of Community Mental Health and Administrative Nursing, School of Nursing, UCSF.

## 8. NUMBER OF SUBJECTS: 30

## 9. STUDY FUNDING: UNIVERSITY OF BOTSWANA AND/OR ROCKEFELLER FOUNDATION

## 10. EXPEDITED REVIEW CATEGORY NUMBER 11

11: PRINCIPAL INVESTIGATOR'S
SIGNATURE------------------------Linda Chafetz------------------------

# APPENDIX F: Information Sheet

The University of California, San Francisco

Family Psychiatric caregiving in Botswana: Experiences, demands, and social support

Information sheet

Esther Seloilwe, a third year doctoral student in the UCSF school of Nursing working under the direct supervision of Dr. Linda Chafetz, DNS, Department of Community Mental Health and Administrative Nursing is conducting a study on family psychiatric caregiving in Botswana. Her intention is to find out the experiences of the family caregivers for the mentally ill, the demands they encounter, the kind support available to them, how the support resources have been utilized, and some extend how this care has impacted on the well-being of the mentally ill person as well as the family.

I am being asked to participate in this study because I have provided care for a mentally ill relative at home. If I agree to participate in the study, Esther Seloilwe will interview me in a private room and in a place convenient for me about two hours. She will ask me about my experiences, demands, and support that I have received from other people, the kinds of things that have helped me and those that have made caregiving more difficult. She will also ask me what kind of advice would I provide to potential caregivers to the mentally ill people in the home.

Participation in this study may involve some loss of privacy, comfort, and confidentiality. To avoid this, the data will be kept anonymous. Code numbers will be used to identify the interview to ensure that data cannot be traced to me. To ensure privacy, I will be interviewed in a place convenient and comfortable for me. I can choose not to answer any questions directed to me and I can stop the interview at any time.

There will be no direct benefits to me from participating in this study. However, my participation may assist mental health professionals to develop strategies that can help other families to provide better care to their mentally ill relatives at home. I am free to choose not to participate in this study and there will be no cost and no reimbursement to me if I take part in this study.

I am free to ask any questions about the study and if I still have any further questions I may contact Esther Seloilwe at 267-351836 (telephone in Botswana), Naomi Seboni at 267-351151 or Linda Chafetz at 415-476-2726 (California, US). If for any reason my questions are not answered, I may contact the Committee on Human Research which is concerned with the protection of volunteers in research projects. I may reach the

Office of the President between 8 A.M. and 5 P.M., Monday to Friday by wrting to The Office of President, P/Bag 001, Gaborone or by personnally going to this office. The Committee on Human Research can be reached by calling 415-476-1814 or by writing to the Committee on Human Research, Suite 11, Laurel Heights Campus, Box 0962, University of California, San Francisco, CA. 94143-0962

# APPENDIX G: Permission Letters (Botswana)

TELEPHONE: [redacted]
TELEX 2655 BD

REPUBLIC OF BOTSWANA

GABORC

TEl: 350807 December 21, 1995

OP 46/1 L (113)

Mrs. Esther Salang Seloilwe
University of Botswana
P/Bag 0022
Gaborone

Dear Madam,

**RE: APPLICATION FOR A RESEARCH PERMIT**

Your application for a research permit dated November 16, 1995 refers.

I am pleased to inform you that you have been granted permission to conduct research entitled "Family Psychiatric Caregiving in Botswana: Experiences, Demands and Social Support". The study will be conducted in Gaborone and Molepolole.

The permit is valid for a period not exceeding sixteen (16) months effective December 20, 1995.

The permit is granted subject to the following conditions:

1. Copies of any papers written as a result of the study shall be directly deposited with the Office of the President, Ministry of Health, National Archives, National Institute for Research and National Library Service.

2. You maintain full and unrestricted liaison with the Ministry of Health.

Yours faithfully

J. Mosweu
<u>for/PERMANENT SECRETARY TO THE PRESIDENT</u>

cc. District Commissioner, Gaborone, Molepolole
Government Archivist
Director, National Library Service
Director, National Institute for Research
Permanent Secretary, Ministry of Health

JM/ck

TELEGRAMS: [illegible]
TELEX: 2818 CARE BD
REFERENCE:

REPUBLIC OF BOTSWANA

*MH.13/18 XIX (43)*

*22nd November, 1995*

*Mrs Esther Seloilwe*
*University of Botswana*
*Private Bag 0022*
*GABORONE*

*Dear Mrs Seloilwe*

***RE: PERMISSION TO UTILISE THE PSYCHIATRIC CLINICS TO ACCESS FAMILIES OF MENTALLY ILL PERSONS***

***Your letter of 8th November 1995 refers.***

***You are hereby granted permission to utilize psychiatric clinics in Ministry of Health hospitals for accessing families of mental patients for purposes of your research.***

***Presentation of this letter to the Hospital Management of the different hospitals should serve as introduction.***

***Yours sincerely***

***E. T. Maganu***
***PERMANENT SECRETARY***