CHAPTER 1

INTRODUCTION TO THE STUDY
1.1 INTRODUCTION

The aim of this chapter is to introduce the study, starting from how I became interested in the subject matter under study, the development of the research question, the significance of the study, the steps taken to conduct the study and how the study findings are presented.

1.2 HOW I BECAME INTERESTED IN THE ISSUE UNDER STUDY

I am a Clinical Nurse Consultant, who has worked in the area of mental health for seven years. I have worked in different clinical areas, including adult and adolescent psychiatry, in both acute and rehabilitation settings. I have been in direct contact with the families of persons with mental illness. Most families wanted to know more about the diagnosis and prognosis of their relative with mental illness. Furthermore, they continuously complained of their inability to manage the unpredictable behaviours of the person with mental illness, and that their lives had completely changed since their loved ones became mentally ill. I also noticed that many caregivers complained that health care professionals did not pay sufficient attention to the caregivers’ needs.

During my work, I have been in contact with many patients and their families who come from a different cultural background, including Arabs. Once they recognized that I was from a similar cultural background, they approached me directly seeking information about their relative with mental illness. They felt that it was easier for them to communicate with a nurse who understood and respected their cultural background. My being bilingual made it easier for families of persons with mental illness to communicate and express their concerns and feelings openly, without being misunderstood or misjudged by a person coming from a different cultural background. Therefore, it was easy for me to establish and maintain rapport and trust with them.

On the other hand, I have also noticed that nursing staff often found it difficult to communicate with patients or their families who came from a different cultural background. This was because of the language barrier and cultural differences such as, beliefs, values and practices, which widened the gap between service providers and service users.
During my observation of the interactions between nursing staff and families of the mentally ill, I noticed that nurses were unaware of the cultural differences, thus considering the way families reacted and communicated with them as difficult, strange or funny. These observations directed me to conduct this study with the focus on a specific culture, the Egyptian culture, in order to understand what it means to be caring for a relative with mental illness from the caregivers’ perspectives. In addition, I hoped to raise nurses’ cultural awareness of clients who come from an Egyptian background, which is similar to other Arab countries, and to help them communicate effectively with these clients.

Initially, my interest was in the caregiving experience in general. However, after reading extensively on the caregiving experience, I found that the literature on caregiving among ethnic groups was limited. After discussion with my supervisor, we agreed on the need for more research to address the caregiving experience from a specific cultural perspective in order to fill in some of the gaps in the literature. The choice was made to examine the caregiving experience for a person with mental illness in the Egyptian families living in Australia. My background played a role in the decision to choose the Egyptian culture as the focus of inquiry. I come from an Egyptian background, which has implications for the study in that both researcher and participants share the same linguistic and cultural background. The researcher’s background and prior understanding of the Egyptian culture was brought into the study.

What directed me to examine Egyptian caregiving, was that little is known about the Egyptian caregivers’ experience in caring for a relative with mental illness in Australia. This includes how these carers cope with their roles as caregivers, their social and cultural beliefs, values and practices.

1.3 THE RESEARCH QUESTION

Based on the gaps identified in the literature, my cultural background, and my experience in working with clients and families who come from diverse cultural
and linguistic backgrounds, this study aimed at finding answers to the following question: *What is it like to have and care for a relative with mental illness in Egyptian families living in Australia?* Therefore, the purpose of the study was to interview relatives and describe the experience in relation to this question.

### 1.4 SIGNIFICANCE OF THE STUDY

- No studies on Egyptian families caring for a relative with mental illness in Australia have been identified in the literature. Therefore, this study explores a phenomenon about which little is known.

- The findings of this study have the potential to increase not only nurses’ understanding of Egyptian culture, but also the understanding of other health care professionals. Therefore, the findings of this study can be transferred and applied to different disciplines and different health care settings.

- The findings of the study direct mental health staff attention to the needs of carers in general and Egyptian carers in particular, thus opening ways to help these carers in their role.

- This study show-cases the real stories of Egyptian families caring for a relative with mental illness in Australia and the meaning of caregiving. It is through these truthful and unique stories that we may gain knowledge of Egyptian culture and Egyptian families living in Australia.

### 1.5 AN OUTLINE OF THE THESIS

#### 1.5.1 CHAPeR 1 - INTRODUCTION TO THE STUDY

Chapter 1 provides a brief description of each chapter of this study.

#### 1.5.2 CHAPeR 2 - REVIEW OF THE LITERATURE

This chapter introduces the topic under study, that is, the caregiving experience of Egyptian families caring for a relative with mental illness. The first section addresses
many of the important aspects that characterize the Egyptian culture. This includes describing the Egyptian family, its structure, functioning, how members relate to each other, and Egyptians’ attitudes, beliefs, and practices related to mental illness. However, due to the lack of studies examining the caregiving experience within Egyptian families, the literature on caregiving is reviewed in general in the second part of this chapter. This includes the effects of caregiving on families, the distinction between subjective and objective burdens, and the factors that influence the caregivers’ coping; for example, the caregivers’ age, gender, social class, education, the availability of social support, religion/spirituality, among other factors.

1.5.3 Chapter 3 - The Research Process

The first section of this chapter provides an overview of the methodology used in this study, that is phenomenology. The reason for choosing this particular approach to examine the caregiving experience is explained. Heidegger’s phenomenology guides this study, focusing on the importance of language, space and time, and the meaning attached to a particular experience. It views participants as having the ability to be self-interpreting. The second section of this chapter includes a detailed description of steps used in the conduct of this study, from gaining the Ethics Committee’s approval to the presentation of findings. This section describes the procedures used in accessing the participants, the criteria for their participation in the study, the ethical issues involved, and the data collection method, which was the interview. The interviews were conducted in Arabic, then translated and transcribed in English. The techniques used for data analysis are illustrated, such as listening to the tapes, comparing the transcribed data to the audio-taped interviews for accuracy of meaning, reading the transcribed data several times to obtain the meaning of the experience as expressed by the caregiver, looking at any similarities/patterns and/or differences. The steps used to analyse data are based on the hermeneutic circle, which is about interpretation of data. Issues of rigour in the conduct of this qualitative research study are discussed, including the steps used to achieve auditability and credibility of the study’s findings.

1.5.4 Chapter 4 - The Experience

This chapter introduces the participants and their backgrounds. It provides a summary of each participant’s story, including their immigration to Australia, their
life before and after immigration, the nature of the relationship between participants and their relative before and after the illness, and how long they have been caring for their loved ones. The major findings of the study are presented. This includes caregivers’ experiences, feelings, thoughts, attitudes, and practices.

1.5.5 CHAPTER 5 - DISCUSSION
This chapter provides a discussion of the study findings, discussing the similarities and differences between carers’ experiences and the meaning attached to the caregiving experience. The similarities and differences identified in the study’s findings are compared to those found in prior literature. Implications of the study’s findings for nursing practice, research and education are discussed.

1.5.6 CHAPTER 6 - SUMMARY AND RECOMMENDATIONS
This chapter summarizes the main issues raised and experienced by the caregivers. The implications of the methodology used in the study for nursing practice and research are discussed. This is followed by the implications of the findings for nursing practice, research and education. Finally, the strengths and limitations of the study are considered.

1.6 SUMMARY
This study focuses on the meaning of the phenomena of caring for a relative with mental illness among Egyptian families living in Australia. Guided by the philosophical underpinnings of this study, that is, Heidegger’s hermeneutics, the participants’ stories are unfolded as I go through the stages of the hermeneutic circle of understanding and interpretation. This circular process of interpretation and understanding allows me to move backwards and forwards within the participants’ stories, in such a way as to come to a deeper understanding of the phenomena under study. The following chapters will bring us closer to Egyptians’ lives, feelings, thoughts, practices, challenges, struggles and successes in their role as caregivers, in an attempt to understand the phenomena of caregiving as expressed by Egyptian caregivers.
CHAPTER 2

LITERATURE REVIEW
2.1 INTRODUCTION

In Australia, it is estimated that one out of four families has or will have a mentally ill relative at some time in their lives (Australian Institute of Health and Welfare & Commonwealth Department of Health and Family Services, 1997). With the deinstitutionalisation movement, which was accelerated in 1960, there was a shift of patients out of hospitals towards integrating them into the community (Doornbos, 1997; Pejler, 2001; Reinhard, 1994). This means that many families of people with mental illness have to assume the responsibility of being the primary caregivers. This is particularly true of families who come from diverse cultural and linguistic backgrounds, including Egyptian families. Studies show that more than 50% of mentally ill migrant people live with their families (Herrick & Brown, 1998; Lantican, 1997). This is because of family protectiveness; it is cultural that families stick together in times of crisis and sickness, and do not abandon the ill.

This chapter provides a context for the study. The first section emphasises the importance of providing culturally sensitive care to clients and families who come from diverse cultural and linguistic backgrounds and the role of culture in influencing people’s beliefs, attitudes and practices. This is followed by a section on immigration and mental health, which describes the role immigration plays in migrants’ mental health, migrants’ coping strategies with mental illness, migrants’ satisfaction with the health care system and barriers to health care services. The third section describes the context of the Egyptian culture, its beliefs, values and practices, and how family members relate to each other. The Egyptian mental health system is discussed with reference to the history of mental health services in Egypt. The purpose of this section is to introduce the reader to the Egyptian culture. The last section reviews the literature on the experiences, feelings, thoughts and coping strategies of families caring for a relative with mental illness.

2.2 CULTURE AND HEALTH

Similarities and differences exist between cultures. Leininger (1997) asserts in her culture care theory the existence of commonalities and diversities within and between cultural groups. She predicts that by the new millennium, all nurses need to be aware of,
understand, and respect cultures that differ from their own in order to provide culturally congruent care. The importance of incorporating transcultural concepts in nursing practice and in particular mental health has been emphasized. For example, the World Health Organization – WHO (2001), in its current activities, gives high priority to mental health programs designed to serve the multicultural communities, and calls for providing care that is culturally acceptable, and the development of a healthy community for immigrants.

The ability to provide culturally competent care involves cultural awareness, cultural knowledge, cultural skills, and cultural encounters. Cultural awareness requires the awareness of cultural biases and cultural sensitivity. Cultural sensitivity occurs when the nurse respects other people's beliefs and attitudes, without stereotyping people, and without being judgmental (Andrews & Boyle, 1995; DeSantis, 1998; Newman, 1998; Wilson & Hobbs, 1994). It is suggested that nurses avoid imposing their own cultural values and beliefs on clients who come from a different cultural background. This imposition may be due to the nurses belief that their own values are the only correct ones, resulting in disrespect, devaluing, and non-acceptance of others' beliefs and values (Jeffreys & O'Donnell, 1997). This is referred to as cultural biases (Hamilton & Hobbs, 1994). Cultural knowledge involves the active role of health care professionals in seeking an educational foundation about cultural world views. Cultural skill is the ability to conduct cultural assessments, which can be used to carry out relevant and appropriate interventions to meet the clients' cultural needs. Cultural encounter is the process of active interactions with clients from different cultural background (Caminha-Bacote, 1994). Some nurses may assume that they are knowledgeable about other cultures' beliefs, values and practices merely because they have interacted with a couple of people from a specific cultural background. These limited encounters are insufficient to allow for providing culturally competent care to clients and their families, as intracultural variation exists within the one culture (Leininger, 1997; Hamilton & Hobbs, 1994).

To fully understand the meaning of providing culturally sensitive care to immigrants, it is first necessary to understand the meaning of the word "culture". Culture is defined as the
values, beliefs, and attitudes of a particular group with specific characteristics that form the identity of this group. Culture shapes people's values and the way they relate to each other and the roles expected of family members (Boyle & Andrews, 1989; Levine, 1984). Culture is the way a person thinks, feels and behaves, a way of living. Culture is learned and passed on from generation to generation, where a specific group of people shares same values, beliefs and practices. Culture is a dynamic process that produces needs, and can grow and change to meet people's needs (Boyle & Andrews, 1989; Newman, 1998).

Each culture has its own values and norms that govern behaviours and actions. One thing in one culture may be acceptable, whilst in another it is unacceptable. Newman (1998) suggests that nurses need to understand that "differences are normal and to be accepted" (p. 232). Values affect the way certain cultural groups view other people, how they interact with and relate to others. It affects the way people view health and illness and how they deal with it. People's satisfaction with life situations is related to their values and belief systems (Andrews & Boyle, 1995). Levine (1984) adds that values are learned, not something people are born with, but once learned, they are hard to change.

Although each culture shares common or general characteristics that are specific to that particular culture, within each culture there will be some differences among the members of that ethnic or cultural group (Groce & Zola, 1993; Newman, 1998). This is due to factors such as education, age, social status, previous experiences, religion, and gender (Spector, 1991). This is what Lieninger (1997) refers to as cultural care diversity, that is, the differences between and within cultures in relation to the meaning of care, values, beliefs and practices. On the other hand, Lieninger (1997) refers to the similarities between and within cultures as cultural care universalities.

In relation to the caregiving experience in different cultures, Phillips, Luna de Hernandez, and Torres de Ardon (1994) focused on identifying the similarities between two different cultures rather than the differences. Their study aimed at assessing cultural equivalence of family caregiving in the Anglo and Mexican (Spanish speaking) American cultures. Although they found that caregiving is functionally equivalent between the two cultures,
the meaning of caregiving was different. This finding is relevant and supports the qualitative phenomenological perspective, which focuses on understanding the meaning of a particular human experience and the use of phenomenological frameworks to explore cultural phenomena. The findings of Phillips et al. also supported the concepts of transcultural nursing, which consider the universalities and diversities of different cultures. Therefore, it is important to understand the world view about a particular phenomenon of a particular culture. World view refers to the way people view their lives in order to let others in the world around them be aware of their views, in an attempt to help others understand their point of view and practices (Leininger, 1997; Leininger & McFarland, 2002).

As mentioned earlier, culture is described as being dynamic, thus one's values, beliefs, and practices can also change, although not everyone is willing or able to change. Even in the immigration process, the acculturation degree of immigrants differs from person to person. Some immigrants are open to, and accept a new culture, others would preserve and maintain some or all of their old cultural beliefs, values and practices. Boyle and Andrews (1989) point out that acculturation occurs when an ethnic group adapts to the changes they face when living in a different country with all its differences in attitudes, behaviour and values. It is a way of coping and adjustment. However, not every immigrant successfully integrates in the new hosting culture. Consequently, nurses need to be aware of the level of acculturation their clients from diverse cultural background possess, in order to intervene appropriately, and to meet their cultural needs.

The following section deals with issues relevant to immigrants such as loss of social support, ways of coping with a relative with mental illness and the major role religion plays in coping, immigrants' experiences with the health care system, barriers to the health care system and the inability of health care professionals to provide culturally sensitive care as well as other barriers.

In the context of this study culture is defined as the values, beliefs, attitudes and practices of a particular group that are learned and shared and that guide thinking, decisions, and
actions in a patterned way. Culture affects people's interactions with the world. (Leininger, 1978).

2.3 MIGRATION AND MENTAL ILLNESS

Caring for a person with mental illness can be overwhelming and distressing. Distress increases when the family leaves the country of origin and migrates to another country. The family may lose social contact with other family members who were the main source of support. In addition, the role of immigration has been found to be a precipitating factor in immigrants' depression. This is due to the loss of social support, loss of one's social status, the stress associated with settlement in the hosting country, and social pressures (Cox, 1977). Australian studies of suicide in immigrants have shown higher suicide rates among immigrants than among those of the population in the countries of origin (Burvill, 1998; Burvill, Armstrong & Carlson, 1983; Kliwer, 1991; Whitlock, 1971). Thus the immigrant caregiver is at higher risk of developing depression not only because of their caregiving role but because of the immigration process.

The way immigrants cope with problems depends on the availability of support systems, age of immigrant at time of immigration, previous lifestyle, motivation, social and financial status before and after immigration, and spiritual support. As mentioned earlier, families play an important role in caring for a mentally ill relative. Families are the primary source of support among mentally ill immigrants. However, immigrant families who lose contact with other family members may find it difficult to cope with caring for a mentally ill person. Aldwin (1994) believes that the person's appraisal of stress, personal and social coping resources, and other people's reactions, influence the way people cope with stress. Similarly, Donnelly (2002) affirms that it is one's cultural beliefs, values and practices that influence one's perception/appraisal of stress and how people cope. For example, in some cultures, the term "stress" is not common.

Immigrants who come from a higher social class with wealth and power in the country of origin, may not be satisfied with the health service they receive in the new country. This is because they expect to be served first and best, demanding to speak to the high ranking
health worker. Added to this, immigrants from certain countries, including Egypt, may have a negative attitude towards nurses. This is because in these countries nursing is considered a lower class job, and they view some health care professionals who “go out to work for their livelihoods...as clearly below the top of the social ladder...[thus] treated as hired help” (Gorce & Zola, 1993, p. 1052).

Consistent with immigrants’ dissatisfaction with the health care services reported above, are the findings of a survey conducted by Minas, Stuart and Klimidis (1994). Health care professionals were surveyed about the quality of services given to English speaking background (ESB) and non-English speaking background (NESB) clients. They found that 58.8% of respondents rated the quality of services to Australian born to be good to very good, 19.3% rated the quality of service available to NESB similarly. The rest of the respondents rated the services for NESB clients as poor to very poor. The survey also revealed that health care professionals themselves lack the skills and knowledge to deal with people from a different culture (Minas, Stuart, & Klimidis, 1994). Minas et al. (1996) argue that people from NESB lack adequate information regarding the resources available to them in the community and how they can benefit from such services, and how to access them. Accordingly, people from NESB are under-utilising such services. Borbasi (1996) interviewed 26 patients from a Sydney hospital to explore the lived experience of being nursed and patients’ perception of what is quality care nursing. According to the participants involved in this hermeneutic phenomenological study, the expert nurse was defined as the nurse who “will keep the patient well-informed about what is happening, and what is going to happen, and what is expected of the patient, on a regular basis” (p. 225). Borbasi points out that this would reduce clients and families’ stress and confusion level associated with being in hospital. This is especially true with clients who come from diverse cultural and linguistic backgrounds due to lack of information about and unfamiliarity with the Australian health care services.

Lantican (1997) conducted a descriptive, exploratory study to analyze the perceptions of services in an outpatient mental health facility in Texas among Mexican American clients with chronic mental illness. The study found that the lack of bilingual health care
providers was the main reason for under-utilisation of mental health services not only among a particular ethnic group, but also among all ethnic groups. Meiser et al. (1997) found that people from an Arabic background felt more comfortable and at ease when interviewed using their primary language, and were able to express their thoughts and feelings more freely and accurately. Successful communication between participants and health care professionals was attributed to their sharing of a similar culture, and staff understanding of this culture’s traditions, religion, and values.

Language barriers and the families’ lack of knowledge about the health care system are considered major barriers to effective service provision. It is suggested that bilingual health care professionals who are aware of a particular ethnic group would be very helpful in overcoming these barriers to communication and to health care (Lequerica, 1993).

Reasons for non-compliance of ethnic groups to attend an appointment with a health care professional, resulting in discontinuity of care, have been reported. Problems involve the family living far from the health service, cost of transportation, unfamiliarity with transport routes, long waiting lists, overcrowded health care facilities and the reluctance of immigrant families to make relationships with others outside the family and with people whose culture is different than theirs (Lequerica, 1993). The failure of health care professionals to communicate effectively with people from a different cultural background, and their lack of cultural knowledge about other cultures have also been reported as reasons for not using the services. Lefley (1984) found that when health care professionals are trained in transcultural issues, the immigrants’ use of services increased, and their premature termination of treatment was reduced. Borbasi, Hawes, Wilkes, Stewart and Donna (2002) suggested that health care professionals need to apply research findings in their practice and to be involved in setting health care priorities to advance their professional status and in meeting clients’ needs.

This current study is investigating Egyptian families who immigrated to Australia and who are caring for a person with mental illness. To contextualise the study the following
section provides information about Egypt as a country and how it compares with other Arab and Middle Eastern countries. The Egyptian population and its characteristics, religions, communication, the use of time and space, touch and eye contact, mental health system, caring for a relative with mental illness, and attitudes, beliefs and practices associated with mental illness are also discussed.

2.4 EGYPT

Egypt is called “Misr” in Arabic. The capital is Cairo. Egypt is part of the area of the world known as the Middle East. Although Middle Easterners share common features, each country of the Middle East has its own characteristics (Lipson & Meleis, 1983). Whilst Western people often assume that Middle Eastern people are Arab Muslims, this is untrue. Not all Arabs are Muslims and not all Muslims are Arabs. It is estimated that only 25% of the Muslim population in the world are Arabs. The largest Muslim populations are in Pakistan, Indonesia, and the Indian subcontinent, and those are not Arab countries (or Arabs) (Luna, 1989). Many Egyptians do not consider themselves as Arabs, especially the Copts of Egypt, because speaking the Arabic language does not mean that they are Arabs. More than 20,000 immigrant Egyptians have come to Australia since 1945; most of them are Copts. This number has increased to reach 50,000 Copts in Australia (An-Nahar, 1992).

The practice of referring to Egyptians as Arabs is relatively recent. This happened under President Gamal Abd-El-Naser’s government in 1975, when he led the Arab movement, and called all the Arab countries to join forces in defending the Arab nations against intruders (Melies, Lipson & Paul, 1992). However, the Arabic language has been used in Egypt since the Arabs invaded the country in the 7th century. Before the Arab invasion of Egypt, Coptic was the language of both the religious and everyday life of the people. Coptic is the language descended from the ancient Egyptians. By the 12th century, the Coptic language had been totally replaced by Arabic, which became the language for both Christians and Muslims. However, the Coptic language was and is still used within the Coptic Orthodox Church.
Although most of the Middle Eastern countries, including the Arab countries, share common features, each country of the Middle East has its own distinctive characteristics that differentiate it from other countries. Even within the same culture or country, there are differences existing between groups of people, which are due to education, gender, age, family upbringing and other factors. The Egyptians have their own historical and cultural characteristics. The Pharos are the ancestors of the Egyptians, and have influenced the Egyptians' values, beliefs, and practices.

The Christian Egyptians consider themselves to be the descendants of the Pharos. The majority of Christians in Egypt are Copts, who marry exclusively within their own religion. As a result, many Copts preserve in their facial and body features the characteristics of the Pharaonic Egyptians (Encyclopaedia Britannica, 2001).

Because of the diversity among the Egyptians and their backgrounds, for example, Greeks born in Egypt are classified as Egyptians according to the Bureau of Statistics (Saout El-Moughtareb, 1989), for the purpose of this study Egyptians are defined as persons who are born in Egypt, speak Arabic and who perceive themselves to be Egyptians.

2.5 THE EGYPTIAN CULTURE AND COMMUNICATION

The Egyptians cherish family life. The family provides stability, love, support and trust for its members. Often, families show intimacy or care using non-verbal cues rather than verbal messages (Budman et al., 1992). Due to the type of relationship between family members and the trust they share, it is not easy for the Egyptian family to trust someone outside the family and to disclose personal information. However, once trust is built, open communication is easily maintained. For a trusting relationship to develop between an Egyptian and an outsider, the outsider needs to disclose information about him/herself such as background, marital and family status and the like (Lipson & Meleis, 1983).

Middle Easterners including Egyptians can be offended if an outsider starts to ask them direct questions, going straight to the point (Lipson & Meleis, 1983; Meiser, Harding,
Mitchell, Fitzgerald, Steel, & Malak, 1997). Egyptians prefer to first take time to get to know each other for a relationship to be established and before disclosing any personal information to the interviewer. Egyptians are also known for their verbalisation, and their use of silence as a way of respect for another’s privacy (Lipson & Meleis, 1983).

Among the cultural issues that health care professionals need to be aware of when communicating with people from the Middle East, including Egypt, is the use of space. In general, Egyptians prefer when conversing with another person to be as close as half a metre (Lipson & Meleis, 1983). It is the Egyptian way to show respect, interest in the person one is talking to, warmth and a welcoming behaviour, as well as providing privacy. On the other hand, Westerners will be uncomfortable with this closeness and prefer proximity of about 1.5m (Lipson & Meleis, 1983).

The “Arabs are highly affiliative. They give friendship and the need for friends a high priority over schedules, work, and deadlines” (Meleis & La Fever, 1984, p. 76). They view time differently from the Western society. Arabs do not rush to meet deadlines, nor do they plan meetings by a fixed time. The relationship between one another is more important than attending to tasks. The Arabs view a quick termination as rude and inconsiderate; they prefer gradual termination.

Touch is used more frequently among Middle Easterners including Egyptians. They use touch as a way of showing care, closeness, to provide comfort and support to one another, and touch is also used with humour when having a good time. However, special consideration must be given to the use of touch with the opposite sex. This is culturally considered inappropriate behaviour and can be misunderstood as having sexual overtones especially if the person is young. Arab males feel uncomfortable when being touched by a female nurse. The same happens if the nurse is a male communicating with an Arab female (Lipson & Meleis, 1983).

Direct prolonged eye contact is considered impolite or conveying aggression. Muslim women are not expected to maintain eye contact with men; it is a way of showing
modesty. It is suggested that people should be aware of both the verbal and non-verbal behaviours of others who come from different cultural backgrounds. This awareness is necessary to create good communication and to hinder any misunderstanding. This is because what seems rude in one culture can be a way of showing respect and care in another culture (Andrews & Boyle, 1995; Luna, 1989).

The Egyptians are known for their generosity and hospitality. They will offer a drink or a meal to strangers/visitors, as a way to express warmth, closeness and acceptance. It is considered rude to refuse to eat or drink with them. This would be seen to reflect coolness and distance. The offering and acceptance of food or drink is culturally symbolic of closeness, one's acceptance of another, and of trust (Lipson & Meleis, 1983).

From the above it is clear that there are many cultural differences between the East and the West in the way people relate to each other and in their use of space, time and touch, that may impact on their access to and use of services based on western understandings of individuals and relationships.

2.6 THE EGYPTIAN FAMILY
In the traditional Egyptian family, children live with their parents until they get married, and the relationship continues after marriage. Parents and older people in general are respected by younger generations. They go to the older people in the family, such as a grandfather or a grandmother, to seek advice and help. Within the Egyptian family, the more a person ages, the more they are seen as wiser and more experienced, and their advice and knowledge is highly appreciated and considered useful. Traditionally, the parents look after their children until they get married. Even after marriage, parents still provide care to their children and grandchildren, financially and emotionally. This continues until the parents get older, then at this stage, the role is reversed, and children are expected to care for their older parents (Luna, 1989). This is reflected in the Egyptians' reluctance and non-acceptance of sending their elderly parents to a nursing home. Elkholly (1981) points out that senility of the elderly occurs rarely in the Middle East, because “...the elderly gain status with age rather than experiencing loss of self-
esteem and self-worth as is often the case with the elderly in Western cultures” (Elkholly, 1981, p. 158).

The Egyptian family is an extended family, where family relationships are highly valued. Family members often gather, meet, and celebrate together, sharing happiness and sadness. The Egyptian family does not abandon a sick relative even if the demands and responsibilities of caring are exhausting. It is expected that all the family members will visit this person, and provide emotional support to the family; sometimes, financial support is also provided. Putting emphasis on family relationships, the family’s duty is to care for the sick member (Luna, 1989; Meleis & La Fever, 1984). Usually a person puts the needs of others, such as the family’s needs, in front of their own (Luna, 1989). Hence, the extended family forms the basis and the primary source of providing support by all its means to its members.

The extended family is more tolerant of their relative’s sick/bizarre behaviour with the attitude of ‘masleesh’, which means ‘never mind’ in English. Emotional and behavioural problems may not be perceived as mental illness among Arabs. The difficulties in recognizing emotional and behavioural disturbances are further increased by the patients’ tolerance of their symptoms and by their families’ tolerance of their behavioural problems. Some people believe that getting the person with mental illness married, usually to a family elder, will force them out of their withdrawal (Meleis, Lipson & Paul, 1992).

El-Islam (1979) conducted a study comparing schizophrenic patients living in extended families in Qatar (n= 155) and those living in nuclear families (n= 117). The participants’ age ranged from 20-35 years, excluding clients with a history of alcohol or drug abuse. El-Islam found that people with mental illness exhibit lower rates of withdrawal symptoms when living with extended family than when living in a nuclear one. The family’s commitment to their mentally ill, the ongoing attempts by various family members to show interest in and establish relationships with the person with mental illness, tended to work against the withdrawal symptoms of mental illness.
Similarly, Seligman (1985) conducted interviews with 30 health practitioners, university faculty members, researchers and program planners in Egypt. The aim of those interviews was to learn more about the nature and availability of mental health services in Egypt and about Egyptian attitudes towards normal and abnormal emotional development. She found that families play a major role in ‘normalization’ of the person with mental illness. This was because most of the leisure time is spent with the extended family; thus, the person with mental illness was not left alone (Seligman, 1985). The findings of the El-Islam and Seligman studies reflect the similarities between Qataery and Egyptian ways of dealing with mental illness, and show that there are similarities between cultures.

In families with a relative with mental illness, people turn to God when social support fails. For example, the Muslim Egyptian believes in fate and that no one can escape from his/her fate. Illness is viewed by some as the result of one’s sins and is a punishment from God. Others believe that it is a way of healing the soul; the family will return to God and pray and ask God’s help for strength or to heal their sick relative. This is due to their faith in God’s power to cure the sick, which is also a Christian belief. However, having faith in God who has the power to cure the sick is having hope. Hope is used as a way of coping with illness (Lipson & Meleis, 1983).

Egyptian families reject long-term hospitalization or institutionalization as it is viewed as abandoning their sick relative (Budman, Lipson & Meleis, 1992; Okasha, El Akabawi, Snyder, Wilson, Youssef & Seif El Dawla, 1994). The Egyptian family will accept other support for their mentally ill relative such as social skills, occupational or vocational training (Okasha et al., 1994). However, the lack of such services that can provide culturally sensitive care or the lack of knowledge about the existence of such services makes it difficult for the family to cope with the caregiving role (Budman et al., 1992). Furthermore, one of the reasons that prevent families from accessing mental health services is their resistance to making any relationships with others outside the family and with people whose culture is different from theirs (Goldstein & Griswold, 1998).
In the Egyptian family, there is opportunity for the younger generation to interact with older generations. However, it is also more likely that intergenerational conflicts arise, as a result of parents’ strict/protective styles, or the older generations’ adherence to traditional norms and ways of thinking, which may differ greatly from those of the younger generations (El-Islam, 1979; Hertz & Gullone, 1999; Klimidis & Minas, 1995; Seligman, 1985). This intergenerational value conflict may be higher amongst older Egyptian migrants and younger generations because of the acculturation process and the bigger age and educational gap between different generations (El-Islam, 1982).

Conflict also arises when a child who is expected to look after his/her elderly parents becomes mentally ill. The child becomes dependent on the family. This role reversal, the associated conflict and disappointment resulting from parents’ expectations of their children, the criticism the mentally ill people receive due to their inability to fulfil their parents’ expectations were among the reasons for their relapse. Findings of the Okasha, et al. (1994) study showed a higher relapse rate among Egyptians with depression, which was related to a higher level of family criticism or expressed emotion compared to Western patients with depression. This is because depression is attributed to personal weakness, which is seen as under the control of the person.

A higher relapse rate was noted among the Egyptian male patients. This was attributed to the higher level of criticism males receive due to their failure to meet the social expectations for males as breadwinners. It was argued that females in the Egyptian culture are generally subjected to higher criticism than males and are thus used to criticism. On the other hand, the family’s attitude towards males is different, where “...criticism or comments are directed sparingly and with great care, so as not to injure the male dignity” (Okasha et al., 1994, p. 1004). However, when the male becomes sick, the family becomes more critical. Budman et al. (1992) argued that this is because Arabs have high educational expectations for their children and they view education as a means to gain respect, become recognized, and have social status, wealth and power. However, El-Islam (1967) argued that criticism in any Egyptian family is an accepted behavior in
interpersonal relationships. Furthermore, it is sometimes considered as a sign of care. Therefore, it is difficult to compare findings of research across cultures.

Another reason for mental illness relapse among Arab Muslims is non-compliance with medication due to religious beliefs and practices. This is because some medications contain alcohol; accordingly, the Muslim patient may be reluctant or non-compliant with medication. In Ramadan, the ninth month of the Muslim calendar, every Muslim has to fast for 30 days. According to their belief, fasting is a way to get fit, become closer to God, and is good for self-control. After 30 days of fasting, the Muslims celebrate the Feast. This is a social occasion where all families gather together and celebrate. These religious observances may interfere with the medication regime as the person cannot have injections or take anything at all in their mouth (Qureshi, 1995).

In Omeri’s study of care and Iranian immigrants (1997), it was found that it was the Iranian culture with all its traditions rather than religion that influenced the family’s care. On the other hand, in studying Arab Muslims and how religion influences people’s care beliefs, Luna (1989) found that the family’s commitment to provide care to their sick relative is due to the religious beliefs among Arab Muslims. It can be argued that the Islamic religion is not only considered to guide the spiritual part of the Muslims’ lives, but is also regarded as law. The Islamic law, in its application, constitutes a system of duties carried out by a Muslim by virtue of his/her religious belief. The Islamic law also constitutes the ethical standards and legal rules that govern Muslim peoples’ behaviours and their social lives such as family law, succession law, education and arts. Thus, whatever Muslims do or not do is based on their Islamic teachings. In this, it is not the society who shapes or makes their own law, but it is the law that precedes and controls society (Encyclopaedia Britannica, 2001). Thus Islamic religion influences culture. Therefore, it is important to understand people’s religion, and culture, and to be able to identify the similarities and differences between cultures.

2.7 THE EGYPTIAN CULTURE AND MENTAL ILLNESS

2.7.1 Services
Cairo, the capital of Egypt, has been and still is the centre of mental health research and teaching for the Arab world. It is estimated that 70% of the mental health professionals in the Arab countries are Egyptians (King, 1983). Mental health services in Egypt are free, except for services provided by private practitioners. With better treatment methods, care of the mentally ill has shifted towards community-based services and the acutely mentally ill are cared for in psychiatric units within general hospitals. Many families prefer to contact psychiatric units in general hospitals for the first episode of mental illness, rather than contacting psychiatric hospitals. They do so because this carries less stigma (Okasha, 1990). Typical clients may suffer from schizophrenia, depression, anxiety, or substance abuse (King, 1983). There are more female clients than males treated as outpatients. This reflects Egyptian values, in that it is more acceptable for women to seek help, but males are expected to be strong and to protect the family's name and reputation from being stigmatised or discriminated against due to mental illness (Seligman, 1985). There is a false belief in relation to treatment of mental illness, especially the use of electro-convulsive therapy (ECT). Although there is a dramatic response to ECT, people are still reluctant to use it because of the belief that it is only given to mad people and will attract a bad reputation. Another false belief is that the person receiving ECT will need to have it for life and will be dependent on it (Okasha et al., 1968).

In big cities, community care takes the form of hostels, day centres, rehabilitation centres and health visitors. The family though remains the main source of providing support and care to their loved ones. In rural areas, community care is implemented without the need of health care workers. Families of mentally ill people have a special tolerance for their loved ones. Families rehabilitate their mentally ill relative by involving and supervising them in cultivating and planting the countryside along with other family members (Okasha, 1989). Therefore, people with mental illness are not left out, but integrated into the community, participating in social activity or suitable work. This keeps the person with mental illness occupied in something useful, thus reducing his/her withdrawal symptoms resulting from the illness. The person with mental illness does not work alone on the land and/or farm, but with other family members. This encourages interaction and
a sense of belonging to the rest of the family. From the above, it can be concluded that people with mental illness are not left alone whether they are in rural or urban areas.

Okasha, Kamel and Hassan (1968) conducted an Egyptian descriptive study of 1,000 clients with mental illness who were attending Ain Shams University Psychiatric Clinic. Clients came from different places in Egypt. Some were referred by general practitioners for a psychiatric opinion, others came from medical outpatient clinics and the third group were self-referred and most of them came from the countryside, after they had tried traditional healers and their condition did not improve. The age of participants ranged from 20-30 years, most were married and males (representing 57.4%). All social classes were represented, although the upper classes were the least represented. Okasha et al. found a lower relapse rate, better response to treatment and better prognosis in general among the people with mental illness who were living in the countryside. They attributed this finding to the family surroundings and cohesion of the Egyptian community. This finding is also supported by Lefley (1990) who found that living in an extended family provided an emotional and economic buffer against the demands of mental illness as compared to the nuclear family who had to endure all these stressors. It could be surmised that it is much harder for immigrant caregivers as well as the mentally ill person to cope on their own, as a result of living in a nuclear family with the consequent loss of extended family and social support.

2.7.2 Attitudes to Caring in the Family

Although mental illness is stigmatised in all cultures, this stigma may be much more pronounced among the Egyptians. Mental illness (al’amrad al’aqliaa - literally translated as illness of the brain) is highly stigmatised among Egyptians. Meiser and Gurr (1996) conducted a qualitative study using focus groups and in-depth interviews with Arabic, Greek and Italian speaking communities in Australia to explore community perceptions of mental illness. They found that Arabic speaking communities, including Egyptians, were strongly reluctant to refer to their own experiences in the context of mental illness. When referring to their problems or those of their family, participants spoke of mental health problems (al’amrad al’nefschiaa – literally translated as 'illness of the self') as
opposed to mental illness. The term “mental illness” was confronting to them (Meiser & Gurr, 1996, p. 46). The study also found that depression, anxiety and eating disorders were not regarded as mental illness, but were given social explanations. However, when a person’s behaviour was out of control, it was described as mental illness. On the other hand, the concept of “mental health problem” was referred to when the person in question was under stress or unable to express himself/herself. People in their study also admitted that they would be scared to talk to a mentally ill person (Meiser & Gurr, 1996). Al-Awadi (1993) pointed out that for cultural reasons or associated stigma, mental illness was not acknowledged and was often construed in other idioms of distress. For this reason people might be reluctant to talk about mental illness.

Okasha et al. (1994) found that Egyptian people viewed depression as some personal or personality weakness and laziness, unlike other mental illnesses such as schizophrenia, which was viewed as an illness. Others attributed mental illness to exposure to sudden fright, possession of evil spirits, head accidents, emotional trauma and to heredity. Therefore, people would try to hide from others that they had a mentally ill person in the family. They did this for fear that having a mentally ill relative would bring a bad reputation to the family and that people would believe that the family had bad blood, which would be inherited in the following generations. This in turn would jeopardize their daughters’ chances of getting married (Gorce & Zola, 1993; Lipson & Meleis, 1983).

Families, out of concern and care might keep the person with mental illness away from others. They might hide their relative to protect him/her from other people’s ridicule and insults. Another reason for this behaviour among immigrants might be their fear that their mentally ill relative would be taken away against their will and placed in a psychiatric institution. This is because it is a standard practice in the countries they come from (Gorce & Zola, 1993).

Mental illness resulting in suicide is highly stigmatised among Christians and Muslims. There are verses in both the Bible and Quran which forbid the killing of self as well as
others as this act is considered a sin against God. For example, Sarfraz and Castle (2002) pointed out that Islam considers life as a sacred trust from God; the individual has no right to end it. The Quran, source of supreme law for Muslims, says “Do not kill yourself, for God (Allah) is compassionate towards you. He who does it in transgression and wrongfully, will burn in hell” (p. 49). They added that since most Islamic states include Sharia (Islamic Law) in their legal system, suicide and parasuicide are criminal offences. Consequently, suicide creates feelings of guilt, shame, anger, sadness in people. Because of the police involvement and legal complications due to suicide, it brings public disgrace to families.

2.7.3 Folk Beliefs and Practices
Egyptians may preserve folk beliefs and practices which are passed on from generation to generation and which may appear strange to the outsider. Middle Easterners, including the Egyptians, may attribute the cause of sickness to the evil eye of the jealous or envious person, magic use and evil spirit possession. Some may wear a blue bead to protect against the evil eye or ‘ein-el hasoud’ in Arabic (Lipson & Meleis, 1983), or figures involving the number five, such as the hand symbol (El-Islam, 1982); others may resort to the zar cult as a way of expelling the evil spirits and/or magic (Abu-Lughod, 1993; Al Awadi, Martin, Al-Salmi & Ghassani, 2001; Mallery, 1999; Somer & Saadon, 2001; Witztum, Grisaro & Budowski, 1996).

The next section describes the zar, a superstitious ritual, which is claimed to be therapeutic in certain situations and with certain people.

In her study of the Egyptians’ self, spirit possession, and world view, Nelson (1971) pointed out that evil spirits are referred to as jinn, shaytan, afreet or asiyad which possess certain people who are “vulnerable to the envy and jealousy of others, including the spirits” (p. 197). In order to pacify and satisfy these evil spirits, people turn to the zar so that the evil spirits do not harm people. In Nelson’s study (1971), one informant explained why people believe in the existence of spirits. He stated that the Koran refers to the spirits as jinn and they belong to God, so therefore there was nothing wrong in

Chapter 2 – Literature Review
believing in them. Younis (2001) pointed out that jinn or demons are commonly believed to be the main causative factor in mental disorders among Arab people, which leads to the practice of exorcism through the zar cult. Therefore, it is not surprising that some Egyptians relate mental illness to spirit possession and they use the zar to cure/manage mental illness.

Zar means “visit” in English. The zar is not a religious act; it is, in fact, in contradiction to religion (both Christianity and Islam). The Egyptian government set policies in an attempt to suppress its occurrence (Okasha, 1966). Despite these attempts, the zar practice is still taking place to date in Egypt as well as in other places around the world (Al-Awadi et al., 2001; Rammah, Serour, Hasanein, Farag & Nassar, 1997). The underlying causes for the acceptance of these folk methods are folk traditions such as customs and trends, credulity and vulnerability of people and the failure of long-term medical treatment (Rammah et al., 1997).

The zar cult is described as the belief in evil spirits which possess a person causing unhappiness, misfortune, and mental and physical illness. Once these spirits enter a person’s body they are called asyaad (masters), and they can never be expelled, only appeased through the use of zar. It is believed that the possessed woman has a karin (male jinn-mate) the spouse who lives underground, and the possessed male has a karina (female jinn-mate). The karin and karina get jealous of their doubles on earth and can be harmful, powerful and dangerous to the person being possessed by them. The “sheikh” priest or “sheikha” priestess recommends that the possessed person have a zar. During the zar, sacrifices such as birds, fowl or animals are given to please and pacify the evil spirits. The sheikh or sheika gives an amulet called “hegab” in Arabic to the possessed person to wear throughout his/her life as a means of protection (Grisaru et al., 1997; Nelson, 1971; Somer & Saadon, 2001).

Results from Rahim’s (2001) study on the socio-demographic characteristics of female psychiatric patients in Sudan who practised zar, showed that generally women who attended the zar were from the lower class, and are referred to as “nas-baladi”; they were
unemployed, never married or divorced, had a family history of practising zar, and had endured stressful life events such as marital dissatisfaction, infertility, child loss, interpersonal conflicts and chronic somatic ailments. The zar was originally practised by Sudanese and Abyssinian slaves in the Egyptian/Turkish upper class harems in the late 19th century (Nelson, 1971). Nelson (1971) illustrated that during her attendance at one of sheikh Mehanna’s zars (a man known as having the power to heal-or ragil baraka), there was a man attending the zar to seek help. Before the zar, he had stayed in a psychiatric hospital for a while; after being released he attended a zar and from that time he declared himself to be well and happy. Nelson stated “he claims that if he absents himself from attending the zar for a long time he becomes very distressed and unhappy” (p. 203).

Studies on zar showed that about half of those who attended the zar suffered from hysteria and fits, which were mainly attributed to spirit possession (Okasha et al., 1968; Sendiony, 1974). Similarly, Rahim’s (2001) study revealed that zar attendance had a favourable response in psychiatric women who suffered from conversion dissociative disorders and some anxiety disorders. Okasha’s study (1966) found that the zar could actually help people suffering from “hysterical reactions, anxiety states, mild depression and organ neurosis” (p. 1219). The underlying interpretation of the zar as a healing ritual is based on the mental and physical changes which take place when the person is attending the zar (Witztum et al., 1996). Al-Adawi et al. (2001) believed that the use of zar might represent a mechanism of psychological manipulation for healing distressed and oppressed individuals and could be a form of culturally defined group therapy. In his explanation of why the zar worked with some people, Okasha (1966) referred to Pavlov’s observations on his dogs during the Leningrad flood in 1924, and how the brain might be wiped clear, at least temporarily, of all the conditioned behaviour patterns recently implanted in it. Applying this to humans and for this conversion to happen, the person needed to have his/her emotions worked upon until the person reached an abnormal condition of anger, fear or exhaustion and became susceptible and easily persuaded. Added to this, a sudden complete inhibitory collapse might bring about the suppression of previously held beliefs.
This phenomenon is similar to many successful modern psychiatric treatments. All the different phases of brain activity, from an increased excitement to emotional exhaustion and collapse in a terminal stupor, can be induced by psychological means, drugs or electro-convulsive therapy (ECT). The best results occur from the inducing of states of protective inhibition by continuing artificially-imposed stresses on the brain until a terminal collapse or stupor is reached, after which it seems that some of the abnormal patterns may disperse and healthier ones may return. This is usually what happened in the zar (Okasha, 1969), which may explain why some clients of the zar state that they feel better after the zar, and their dependency on attending the zar regularly. During the zar, the person experiences marked excitement accompanied by dancing, repeated loud beating of large drums, singing and snake-handling, until the person becomes exhausted and collapses. When this occurs, it is believed that the person is possessed by asyaad/masters, to whom the illness is attributed.

The collapse of the possessed person is also believed to be a sign of submission to the masters, which in turn satisfies the masters and the evil therefore leaves the person. It is argued that those who fail to improve in spite of practising these rituals are unlikely to be in need of submission to a parent figure. Accordingly, people unconsciously select what to believe depending on their individual and psychological needs (El-Islam, 1967). After the person collapses, the music stops, the kodia approaches the person and enjoins the devil possessing the person to state his origin and demands. The kodia is the only one who can hear the devil, who reveals himself as being a Christian or Mohammedan (Mohammed was the Islamic prophet). Accordingly, a cross or a crescent is drawn using the blood of a slain sheep on the gown of the possessed person. A silver coin is dipped in the same blood and given to the possessed person who will put it in a leather case and wear it all his/her life as a charm. At the end, the kodia asks the devil to leave the possessed person and promises that his demands will be met. A jar is placed in the centre of the room, and it is claimed that when the devil leaves the person’s body, he exits through the jar and the jar breaks, which is a sign for leaving the possessed (Okasha, 1966). Many Egyptians use “bughr” or mist in English to send away any bad or evil
spirits which are believed to be the cause of a person’s mental illness and other misfortunes.

Education plays a role in the way the Egyptian family views and copes with mental illness. The zar cult is practised by people from the lower social classes, who are often illiterate (El-Shamy, 1972; Fakhouri, 1968; Nelson, 1971). It is the level of education which influences the way people relate certain life experiences to spirit possession and the way they handle these situations through zar. For example, in her study, Nelson (1971) related that “... a Cairo University student considers the zar a ‘superstitious tradition’ impeding the country’s progress” (p. 201). Furthermore, sheikh Mehanna’s son, as a Cairo University student, mentioned that he did not believe in zar and that it would end in his family when his father died (Nelson, 1971).

Although people from lower social classes with limited education have been found to believe in the evil eye as the cause of mental illness and to use the zar cult as a means of healing/curing the person with mental illness, the belief in magic and evil spirit possession is not exclusive to people from these classes. People from all social classes may attribute mental illness to magic or evil spirit possession. The only difference is that people from higher social classes may be reluctant to resort to the zar for cure, preferring to seek psychiatric treatment for their mentally ill relative. They may refer to the zar when they feel they have tried everything and nothing has helped. Then they may turn to the zar in despair. In addition, most of the higher-class people have maids at home who in most cases are illiterate or have limited education and who are more likely to have attended and used the zar themselves or attended the zar with relatives (El Sendiony, 1976). It is often these maids who suggest that the family seek traditional healers and resort to the zar.

An overview of the zar cult has been provided here because of its importance in understanding some Egyptians’ attitudes and beliefs regarding mental illness. Nelson (1971) in “Self, spirit possession and worldview: An illustration from Egypt”, and Fakhouri (1968) in “Zar cult in an Egyptian village” discuss the topic at length.
The above section has explored Egyptians' religion, language, communication such as the trust in the family, the importance of relationships, use of space, touch, time, eye contact and food as a symbol of trust. The Egyptian mental health system, family dynamics, attitudes and beliefs regarding mental illness have been discussed. The way Egyptians communicate with each other, and their views of mental illness may seem different from and sometimes strange to people who come from a different culture. From the above, it can be seen that the family is an integral part in providing support to its members in time of need. Families do not abandon their relative with mental illness. The stigma associated with mental illness is very pronounced among Egyptians. Mental illness may be attributed to evil spirit possession, magic, evil eye or may be viewed as a fate which cannot be escaped. People may seek traditional healers and cult practitioners, or seek religious healing; if these interventions do not work, then they may resort to psychiatric interventions. However, some people from upper classes may only resort to zar cult after exhausting modern psychiatric services. It can be concluded that culture plays an important role in shaping people's attitudes, values, beliefs, and practices in the context of mental illness.

The following section of this chapter reviews the literature on caregiving with emphasis on the experience of caring for a relative with mental illness. This includes how families struggle for meaning, their efforts to find a way of understanding and how families care for their loved ones at home and their experiences with the mental health care services. This section on caregiving reveals how families' lives are affected socially, physically, emotionally and financially. The burden of caregiving and issues related to blaming the caregivers or the persons with mental illness are described. In spite of all the changes, sacrifice and burden families face, they survive by using various strategies. Factors influencing people's ability to cope will be discussed, such as the role of social class, diagnosis and chronicity of mental illness, gender and age difference of carers and of persons with mental illness.

2.8 THE EXPERIENCE OF CAREGIVING
While the impact of caring for a mentally ill relative has been documented in the literature (Doombos, 1997; Eakes, 1990; Jones, 1996; Maurin & Boyd, 1990; Rose, 1996), there is a lack of studies examining the experience of caregiving among families of NESB including Egyptian families. Literature on ethnic groups has focused on ethnicity and the diagnosis of mental illness (Flaskerud & Hu, 1992; Franks & Faux, 1990), or on ethnicity and the utilization of mental health services (Herrick & Brown, 1998). As a result of this limitation in research regarding the caregiving experience among migrants, the literature on caregiving in general is reviewed.

The majority of the literature on caregiving has focused on family burden, discussed issues of chronic sorrow, guilt, blame, expressed emotion and has viewed the family as a dysfunctional one (Gibbons, Horn, Powell & Gibbons, 1984; Kuipers & Raune, 2000; Noh & Turner, 1987; Sczaufca & Kuipers, 1998; Tennakoon, Fannon, Doku, O'Ceallaigh, Soni, Santamaria, Kuipers & Sharma, 2000; Veltman, Cameron & Stewart, 2002). Much of the research on expressed emotion has suggested that families may be responsible for the relapse of their mentally ill relative and therefore are to be considered dysfunctional (de Cangas, 1990; Okasha et al., 1994). This reinforces the negative connotations of mental illness and of families of the people with mental illness.

2.8.1 Chronic Sorrow
The term chronic sorrow has been used to describe the grief and sadness families experience over time in response to the loss of a loved one to mental illness, similar to that experienced by families who have a loved one die (Eakes, 1995; Miller, Dworkin, Pharm & Barone, 1990; Mohr & Regan-Kubinski, 2001). It has been defined as "a pervasive sadness that is permanent, periodic, and progressive in nature" (Hainsworth, Eakes & Burke, 1994, p. 59). Sadness and grief is caused by seeing a son or daughter changing from a normal child to a needy stranger (Doombos, 1997, 2001; Tuck, Mont, Evans & John, 1997). The family's distress level increases as the illness progresses and becomes chronic (Doll, 1982; Lefley, 1987; Noh & Turner, 1987). Gibbons et al. (1984) found in their study that 72% of caregivers of relatives with mental illness showed signs of physical or emotional distress, and 32% experienced signs of mental
illness/distress such as anxiety, depression and insomnia. Similarly, in the study by Tennakoon et al. (2000), 12% of caregivers of a person with a first episode of psychosis exhibited psychiatric morbidity. Veltman et al. (2002) found a higher rate of psychiatric illnesses among caregivers. Their study revealed that 8 out of 20 caregivers interviewed were diagnosed with and treated for depression themselves after the onset of their relative’s mental illness. This indicated that caregivers’ distress level was higher at the initial stage of the illness due to uncertainty, shock and lack of skills to manage the person with mental illness. Tennakoon et al. (2000) argued that the nature of the caregivers’ burden was likely to change over time as the illness progressed and suggested that longitudinal studies were needed to examine carers’ burden over time.

In contrast, other studies have found that families learn to adapt to the illness over time and to cope with the burden of caregiving (Robin, Copan & Freeman-Browne, 1979; Winefield & Harvey, 1993). Seltzer, Greenberg and Krauss (1995) believed that caring for the ill person over the years enabled families to manage and adapt to the illness, and families’ expectations for their loved ones became more realistic. They noted that “stressors that are predictable and anticipated are less likely to negatively affect well-being than stressors that are novel and unanticipated” (p. 73).

Similarly, Miller et al. (1990) revealed that families with schizophrenic and bipolar relatives expressed a low level of initial grief, but higher levels of present grief. They suggested that it could be that families go through a delayed grief reaction or suffer unresolved grief. They attributed this delayed grief to the progressive nature of mental illnesses as time goes on, and families suffer more and more losses. They added that families of people with mental illness might not fully understand and contemplate their loss in the initial stage due to confusion, disbelief and hope for a cure for their loved ones. Families started to deal with their losses years later, when they had enough time to fully understand their new life experiences in caring for a person with mental illness, with all its effects on other family members. They also raised the question whether the diagnosis of the person with mental illness affected the level of grief among families but found no correlation between the two. To help families cope with chronic sorrow, Miller
et al. (1990) suggested that nurses needed to explain that the experience of chronic sorrow was a normal reaction of chronicity. With support and identification of positive coping strategies, it was likely that families would experience more comfort and better understand their feelings (Hainsworth et al., 1994). The differences in research findings in relation to families’ coping and adaptation can be attributed to other factors such as financial problems, personal strengths and the availability of adequate support rather than the time factor on its own. Therefore, more research is needed to address the various factors that may have an impact on families’ experience of chronic sorrow.

2.8.2 The Burden of Caregiving

The experience of caring for a relative with mental illness results in the caregivers feeling drained and burdened. The term ‘burden’ is used in the literature on caregiving to reflect the caregivers’ sacrifice in putting the needs of their loved ones above their own (Johnson, 1990; Maurin & Boyd, 1990) and thus ignoring their own needs for the sake of their loved ones. Families experience two types of burden: the objective and the subjective.

Objective burden, which is defined as the observable negative effects of caring for a relative with mental illness, includes physical and/or financial problems, disruption in social life and the constant supervision of the mentally ill person. Subjective burden relates to the families’ personal feelings about the caregiving responsibility, and includes feelings of guilt, distress, powerlessness, fear, embarrassment and the stigma associated with mental illness (Doornbos, 1997; Jones, 1996; Muhlbauer, 2002; Pejler, 2001; Platt, 1985; Provencher, 1996, 2002; Thompson & Doll, 1992).

There are differing definitions of subjective burden. Some researchers interpret subjective burden as the way families perceive the behaviour and dependency of the mentally ill relative as the source of distress (Noh & Turner, 1987; Rungreangkulkit & Chesla, 2002). Others interpret subjective burden as the overworking, feelings of resentment, and isolation (Thompson & Doll, 1982; Veltman et al., 2002); the patient as a source of anxiety, worry, depression and guilt (Pejler, 2001; Reynolds & Hoult, 1984;
Tennakoon et al., 2000); the feelings associated with the patient’s non-compliance with medication, and the dissatisfaction with the mental health system for not providing adequate information and support to families (Doornbos, 2002; Lefley, 1987; Levine & Ligenza, 2002).

In Doornbos’ study (1997), 85 families were involved, with the majority of carers being white married females, ages ranging from 22-76, and 48% of them being employed outside the home. Families’ stressors were measured by the Family Inventory of Life Events and Changes Scale. The findings indicated that one of the problems that families faced was the patient’s non-acceptance of his/her diagnosis, which resulted in non-compliance with treatment, and the patient becoming hardly manageable. Feelings of worry and concern are also experienced by families caring for a person with mental illness. Parents reported the ongoing worry about what would happen to their child with mental illness when they died, about who would look after him/her, especially among elderly caregivers (Hatfield & Lefley, 2000).

In her study of the association between subjective and objective burden, Jones (1996) found that families did not mind doing the housework, managing medication, money, transportation, shopping, cooking, or grooming their relative with mental illness (objective burden). On the other hand, it has been reported that the subjective burden has been the most disturbing and frequent problem experienced by families compared to the objective burden. The most distressing behaviours of the person with mental illness were mood swings, unpredictable behaviour especially when it occurred in public and resulted in embarrassment (Jones, 1996), lack of motivation (Rose, 1983), excessive demands which often resulted in neglect of other family members’ needs (Lefley, 1989), and being uncooperative in carrying out their own tasks, especially self-care (Jones, 1996).

It has been reported that the negative symptoms of mental illness are more distressing to families than the positive symptoms. Examples of the negative symptoms included patients’ lack of motivation, withdrawn and isolative behaviour, with those who do not interact/speak with their caregivers and other family members being found more
distressing to families than those patients with excessive speech (Veltman, 2002). On the other hand, positive symptoms such as hallucinations, delusions and thought disorder were not as distressing as the negative symptoms for families caring for a person with mental illness (Fadden et al., 1987; Shafin & Thordarson, 1995).

Families raised the question “why did it happen to us?” They did not have definite answers to this question. They experienced shock and disbelief at the diagnosis and blamed themselves. Families wondered if they had done something to contribute to the patient’s illness, which resulted in feelings of guilt (Doornbos, 1997, 2002; Lequerica, 1993). Murphy and his colleagues (1965) found that feelings of guilt in Western cultures were related to the influence of the Christian religion. In contrast, El-Islam (1969), who conducted a study examining the effect of religion on guilt among Christian and Muslim families in Cairo/Egypt, found that a feeling of guilt was not directly related to religion. Rather, it was the level of education that provided alternative explanations from self-blame.

The quality of relationships influenced the families’ commitment to caregiving. Pohl, Boyd, Liang, and Given (1995) analysed the impact of mother-daughter relationships on the commitment to caregiving. Data were collected from telephone interviews and mailed self-completed questionnaires, which included mother-daughter attachment and conflict scales and the scales set to measure affective commitment. The sample represented middle-class European American families. The responsibility of daughters to care for their mothers who had mental illness was found to be due to the continuing attachment/bond over a lifetime. This commitment to care further strengthened the relationship among carers and their loved ones. Similarly, Badger (1996) interviewed 11 English-speaking family members who were living with a person with depression, their ages ranging from 32-61 years. Nine out of 11 participants had been caring for a partner with depression for months to years. Findings of the study showed that caregivers, in their protection of their loved ones, used “affirming affection”, that is, providing ongoing reassurance to the person with mental illness that family members still loved and cared for him/her despite the illness. Furthermore, families with a depressed person reported
that they spent more time with their children to compensate for the negative effects of living with a depressed parent. This, in turn, helped to bring family members closer.

### 2.8.2.1 Gender and the level of burden

One of the factors that influenced families' experience of burden was the gender of the caregiver. Some studies showed gender differences in the way caregivers viewed mental illness and in their coping mechanisms (Gonzalez, 1996; Noh & Turner, 1987; Wasow, 1985). These studies found that females were at higher risk of being distressed than males because the majority of caregivers were females (Coward & Dwyer, 1990), and had more responsibilities towards other family members (Noh & Turner, 1987). However, Schulz and Williamson (1991) found that male caregivers exhibited more depressive symptomatology than females over a period of time. In contrast, some studies showed no significant difference between females and males in relation to the burden of caregiving (Gibbons et al., 1984; Jones & Peter, 1992). Noh and Avison (1988) found no gender difference on the overall level of burden among caregivers, but there were differences in the way caregivers viewed and experienced burden. In their study, husbands' burden was associated with the symptoms of their relatives' illness and life stressors, while wives experienced burden as a result of having to care for dependent others (children), their age and their sense of coping.

Other studies examined the effect of carers' gender, in addition to other variables such as age and social support, on the level of burden, and found that a relationship between those variables and carers' burden existed. However, there could be other variables such as the length and severity of mental illness, which could have contributed to the differences in caregivers' distress levels. Brody, Litvin, Hoffman and Kleban (1992) found that married caregivers experienced less burden than caregivers who were unmarried, due to shared responsibilities, more income, thus less financial strain and more socio-emotional support. Those married caregivers reported that the presence of a partner in their lives made the caregiving experience easier.

Blaming the caregivers was more associated with women than with men. In America, Natale and Barron (1994) investigated the relationship between mothers' causal
explanations for their son’s schizophrenia and the depression and guilt mothers experience. They interviewed 33 mothers who were the primary caregivers to a schizophrenic son, using the Casual Dimension Scale and the Multi-score Depression Inventory. Participants were recruited from an agency that conducted educational classes for persons who had a mental illness and their family members. The women who met the criteria of being the primary caregivers for a schizophrenic son, were able to read, speak and write English and had an age range of 45-65. All participants were white high school graduates, and most were married. Where female caregivers of schizophrenic sons did not receive any causal explanations from health care professionals regarding mental illness, they blamed themselves for something they did or did not do, which caused their loved ones to be mentally ill. As time progressed, the mothers’ depression level decreased from what it was at the initial diagnosis, which could be related to the change in the mothers’ expectations of their schizophrenic son. Those expectations were replaced with more realistic ones, which could be achieved by their loved ones (Natale & Barron, 1994).

The literature suggests that not only the gender of the caregivers influenced the caregiving experience, but also the gender of the person with mental illness. Mothers of schizophrenic sons experienced more guilt, sense of loss, and blamed themselves for being responsible for conceiving and mothering a schizophrenic son compared to having a schizophrenic daughter. These negative feelings were found to contribute to mothers’ depression (Natale & Barron, 1994). The feelings of guilt associated with the gender of a child who was mentally ill could be related to societal values which placed greater value on men than women (Schaeff, 1981).

Winefield and Harvey (1993) studied caregiver and patient characteristics and how those characteristics impacted on distress levels. They gathered descriptive information from 134 participants in Australia, using questionnaires. The information was about the contribution of caregiver and patient characteristics to their distress. Hierarchical multiple regressions were performed with indicators of caregiver distress as dependent variables. “It was hypothesized that caregivers’ age, sex, and social support would affect
their psychological state, but that the sufferers’ characteristics, such as length and severity of illness, would explain additional variance in caregiver distress" (p. 620). They found that families caring for a female patient experienced greater distress than those caring for males. The researchers noted that this was contrary to expectations because schizophrenic females displayed less overt acting out than males and hence were less burdensome for their families. Winefield and Harvey argued that it could be that the effect of ill women on their children caused greater anxiety in the carer. For example, women with schizophrenia might be perceived as more incapacitated in caring for their children than were men with schizophrenia or that behavioural expectations differed for the two sexes.

2.8.2.2 Age of carer and the level of burden
The age of the carer also appears to have an effect on the experience of caregiving, although there is inconsistency in research findings about the age factor and experience of burden. Older caregivers in Winefield and Harvey’s study (1993) reported less negative effects, and older female caregivers experienced less burden. It was suggested that the older the carers’ age, the more likely that they had been caring for the person with mental illness for a longer time, thus gaining experience in managing and dealing with the illness. This is contrary to Lefley’s study (1987), which showed that caring for mentally ill adults imposed stress on elderly caregivers, who had diminishing energy, limited finance and control. For aging parents, lifetime caregiving places excessive burden on them, at a time when they need rest and care from others.

2.8.2.3 Diagnosis of mental illness and the level of burden
The diagnosis of the person with mental illness has an effect on families’ experience of distress. Badger (1996) considered that family dysfunction occurred more when the ill person was diagnosed with depression than in schizophrenia or bipolar disorders. More than 40% of adult family members living with a depressed person were distressed to the point of requiring professional intervention. For children of depressed parents, the chances of developing an affective disorder increased to 45% (Buckwater, Kerfoot & Stolley, 1988). Similarly, Meadus and Johnson (2000), who conducted a qualitative study of three adolescents caring for a parent with mental illness, found that the
adolescents taking the caregiving role experienced a serious disruption in family life due to the unavailability of the ill parent. This in turn evoked intense fears, frustration and loss in these young carers.

2.8.2.4 Effects of burden on family relationships
Several studies reported that the burden of caregiving is extensive to the point that it may lead to divorce or separation in marriages where one partner is mentally ill. However, in other marriages, several wives considered separation or divorce, but decided to give the relationship with their husbands a chance to survive (Fadden, Bebbington & Knipers, 1987). Problems in the family could also arise due to financial difficulties and when the breadwinner was mentally ill. These problems were exacerbated if the relative or partner of the mentally ill person were unable to take over the role of providing for the family financially (Veltman et al., 2002).

Having a relative with mental illness affects families in different ways. Most families believed that stigma was associated with mental illness (Kelly & McKenna, 1997; Rose, 1997; Rungreangkulikij & Chesla, 2001; Veltman et al., 2002). Stigmatization of persons with mental illness could lead to limited social activities, and heightened tension between family members (Johnstone, 2001). Families of the mentally ill person were afraid of societal attitudes, and how these attitudes could affect their family status/reputation in the community. They were also afraid that people would discriminate against the mentally ill relative (Mühlbauer, 2002; Pejlert, 2001). Therefore, the stigma associated with mental illness prevents many families from seeking treatment for their mentally ill person in the community (Doornbos, 1997). Many families believed that stigma associated with depression was higher than that of other illnesses as it was attributed to personal weaknesses and therefore was seen as under the patient’s control, rather than biological factors perceived as out of the patient’s control (Badger, 1996). In their study of Asian-American utilization of mental health services, Herrick and Brown (1998) reported that mental illness was viewed as some sort of emotional and behavioural problem associated with youth and life situations, which needed to be kept within the family. Furthermore, the Asian participants’ fear of stigma, and/or their beliefs that mental illness was a sin, or
caused by spirit possessions, witchcraft, or "bad blood", and that seeking help was a sign of weakness, prevented them from seeking professional help.

Having a person with mental illness in the family not only affects the primary caregivers, but also siblings. The effects of caring for a person with mental illness on siblings have been documented. Siblings of persons with mental illness were at higher risk of emotional and behavioural disorders compared to the general population, regardless of the amount of time actually spent in direct caregiving (Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari, 1996; Lieberman & Fisher, 1995; Meadus & Johnson, 2000). Many siblings distanced themselves from the mentally ill as a self-protective and survival mechanism (Fadden et al., 1987).

2.8.3 Burden of Negotiating Health Services

Negotiating care whilst in the hospital results in a far from satisfactory experience. The majority of families, when asked about their satisfaction with the health care system, were dissatisfied with the services. Families complained that health care professionals did not involve them in the care of the patient in the acute phase, failed to give them information about the illness, its prognosis, practical management of the patients' behaviours, about how to cope effectively, and did not provide support. These were the major sources of distress to the families (Chambers, Ryan & Connor, 2001; Doornbos, 1997; Eakes, 1995; Gaff, Atkinson, Elliott & Johansen; Gorman, 2003; Hatfield, 2000; Lefley, 1987; Nolan, 2001; Nolan, Lundh, Grant & Keady, 2003; Rose, 1997; Song, Beigel & Milligan, 1997; Tuck, et al., 1997).

Loukissi (1995) reviewed research studies on family burden in chronic mental illness. Her conclusion of the review was that the majority of caregivers reported that they were faced with the responsibilities of caring for a mentally ill relative without adequate information or preparation to help them in their caring role. Similarly, Lefley (1987) found that caregivers complained of receiving contradictory information from health care professionals, which was a source of distress to them. Reinhard (1994) examined the relationships among professional support, caregivers' personal sense of control, and
burden. A convenience sample of 94 participated in this study, using a 19-item Burden Assessment Scale and a 20-item Centre for Epidemiological Studies Depression Scale to measure depression. Findings of the study suggested families needed affective support from health care professionals such as empathy and respect for their worries and attitudes regarding the care of their mentally ill relative (Reinhard, 1994).

Bernheim and Switalski (1988) reported that caregivers often felt guilty, frustrated and helpless whenever they had an encounter with a mental health professional; thus they perceived them as unsupportive. Families complained of the negative attitudes of mental health care professionals towards them and in the way they viewed families as dysfunctional and psychologically disturbed (Bernheim & Switalski). Families of a person with mental illness experienced significant stress compared to other families without a mentally ill relative; however, they had strengths in managing conflict and in adaptability (Doornbos, 1996; 2001). It would be unfair to label all families of the mentally ill person as dysfunctional or lacking in strengths in their relationship with their loved ones.

Families’ strengths lie in their ability to avoid conflict and confrontation with the mentally ill relative as a way of caring and coping. One of the positive outcomes for families was that people with mental illness who lived with their families could fulfil a productive helping role in the home for their physically aging parents by being a companion (Hatfield, 1997; Lefley, 1987), doing household chores, shopping, assisting financially and listening to problems. The experience was seen as a giving and taking between caregivers and persons with mental illness (Greenberg, Greenley & Benedict, 1994; Ludbrook & Hafner, 1998). Therefore, it is important to acknowledge the contributions of people with mental illness to their families. More research is needed to explore family behaviour and expectations that may affect the positive contribution of the mentally ill to his/her family.

2.8.4 Strategies for Survival
Surviving refers to people’s ability to cope with and reduce their level of stress or life strains (Lazarus & Folkman, 1984). Families used different approaches and strategies to survive. Families who attributed the unpredictable behaviours of the person to the illness itself showed more tolerance and less burden in their caregiving relationship with their loved ones compared to families who blamed the patient for their behaviours (Shafran & Thordarson, 1995).

Social support, caring of the patient in the community, and mastery of the situation were found to reduce the level of stress related to the caregiving role (Noh & Turner, 1989; Schumacher, Stewart & Archbold, 1998). Families who considered themselves to have survived the experience effectively reported that they were members of a support group, were more accepting of their relative’s illness, distanced themselves emotionally from the situation (Badger, 1996), set limits on the patient’s behaviours, and were involved in outside activities (Doornbos, 1997; Rose, Mallinson & Walton-Moss, 2002). Among their coping strategies, families reported that talking to others, expressing feelings, thinking positively, keeping busy (Bland & Darlington, 2002; Eakes, 1995; Tennakoon et al., 2000), and hope, faith and spirituality (Badger, 1996; Bower, 1999; Doornbos, 1996; Pejler, 2001; Rose, 1997; Tennakoon et al., 2000; Tuck et al., 1997) helped them to survive.

Other ways which helped families to survive, included the provision of education. Educational interventions with families of the mentally ill, which included information about mental illness, symptoms, families’ role, and resources available to them, were found to have a positive effect on families (Czucha & McCay, 2001; Sidley, Smith & Howells, 1991). When educational and supportive interventions were used, families experienced less anxiety and personal distress and were able to develop more active coping strategies, such as using community resources to achieve a better quality of life (Abramowitz & Coursey, 1989; Shin & Lukens, 2002). Other studies compared the effect of behavioural and supportive family intervention programs on families’ coping. They found that both interventions reduced conflict in families, raised families’
awareness of the availability of community resources and effected an overall reduction in family burden (Zastowny, Lehman, Cole & Kane, 1992).

In their study of caregivers' depressive symptomatology and the effect of social support on it, Schulz and Williamson (1991) found that caregivers with less social support had higher depressive symptomatology than those with social support. On the other hand, Rivera, Rose, Futterman, Lovett & Gallagher-Thompson (1991) found no significant difference in relation to the role of social support on depressed and non-depressed caregivers. This could be related to the differences in the caregivers' personal strengths and coping skills other than the social support factor. Similarly, Reinhard (1994) found that professional support was not a significant predictor of burden and families' well-being. However, professional support indirectly helped in reducing family burden by increasing the caregivers' personal sense of control.

In general, professional support in the form of increasing the caregivers' sense of personal control and mastery helped in reducing the burden on families. Educating the caregivers about the use of practical strategies, such as the use of limit settings to handle difficult situations with their relative, enhanced their sense of control (Hatfield, Fierstein, & Johnson, 1982). Hence there may be a relationship between personal control and reduced level of distress among caregivers.

More research is needed on the role of professional support on the level of families' distress. This is because most research has focused on how this support can improve the functioning of the person with mental illness, to help them remain in the community, rather than how such support or interventions may help families cope or reduce their distress (Reinhard, 1994).

Some families have used cognitive strategies, such as problem-solving, and behavioural strategies to reduce problems in the family. They have viewed family problems as a normal reaction to life situations and not as signs of family dysfunction (Abramowitz & Coursey, 1989). In her study of families' strengths in coping with mental illness,
Doornbos (1996) found that families' strengths lay in their functional abilities. Functional abilities of the family refer to "the capacity to do what is necessary to function and to preserve its integrity as a family unit" (p. 218). It may be concluded that families of the person with mental illness develop coping and adapting strategies and they learn how to be flexible and able to change according to the different situational and developmental stressors. It is important to acknowledge this as a strength and as an example of healthy families rather than viewing families of the mentally ill as dysfunctional.

It should also be noted that although families in Doornbos' studies (1996, 2002) possessed some strengths in relation to functional abilities, they perceived themselves to be less connected than normative families. This could be attributed to the lack of time and energy of family members to connect and bond due to responsibilities and life stressors. Doornbos suggested that it was important that mental health care professionals organized referral to respite programs, thus allowing other family members to spend quality time with each other and improve family cohesiveness and satisfaction. Further research is needed to identify the support needs of various caregivers and to examine the differences according to kinship relationship (Reinhard, 1994).

Chesla (1989) described the lived experience of schizophrenia, as understood by parents who cared for adult schizophrenic offspring. Twenty-one parents were interviewed. These families worked hard to develop an understanding of their relative's illness, in order to help the person with mental illness cope. Chesla found that parents of schizophrenic children developed various models of care, such as normalization of their mentally ill child by exposing the child to healthy and positive surroundings and reducing exposure to the negative ones. These families believed that the illness was out of the patient's control, and they encouraged their loved ones to reach their potential. They were against socializing their loved ones with mentally ill people or day treatment for the disabled for fear that this would make their loved ones function at a lower level. Other models identified included rational control, where parents used persuasion techniques to help their loved ones to respond to rational thoughts, will power and refusal to give in to
the symptoms. In this, parents hoped that their loved ones would learn to think differently and therefore act differently, thus having control over the illness (Chesla, 1989).

Parents who used the survival-through-symptoms model were less judgmental and less confronting. They were more supportive, accepting and less demanding of the mentally ill to change his/her behaviour. Chesla (1989) pointed out:

_They tried to understand the illness from the perspective of the schizophrenic, and in doing so, they suffered greater pain themselves. Because they understood the symptoms as protective measures, they exhibited extreme tolerance and sympathy with the behavioural manifestations of the illness (p. 224)._

Regarding the role of social class in the survival of families, different findings have been reported. Some researchers found that there was a correlation between the educational level of the person and the level of coping and surviving. They reported that a high stress level was associated with low educational level (Noh & Turner, 1987). Contrary to this finding, Thompson and Doll (1982) found no significant difference between social class and stress level. The only difference they found was the financial burden experienced by the low socio-economic class.

Stewart (1995) suggested that the Asian-American way of coping with stressors was believing in willpower and avoiding negative thoughts; crying was viewed as a weakness and thus avoided. The findings of this study showed that there were some commonalities and differences between cultures that needed to be considered when dealing with people from different cultural and linguistic backgrounds. For example, positive thinking was a common theme identified by caregivers from an Anglo-Saxon and Asian-American background. Similarly, crying was not used as a coping strategy in these two cultures.

Rungreangkulij, Chafetz, Chesla and Gilliss (2002) interviewed 108 Thai families to assess the impact of family factors on psychological morbidity of relatives of a person with schizophrenia, using the resiliency model of family stress, adjustment and adaptation. They found that spiritual support played a role in families’ coping with
stress. Years of illness of the person with schizophrenia (average 7.47) might also influence families’ coping as they learned to manage over time. This finding is consistent with the McCubbin and McCubbin (1996) resiliency model, which consists of two phases: the adjustment phase, which shows how families react to stressors; and the adaptation phase. Families’ response to chronic illness usually extends to the adaptation phase because it evolves over a long period of time and requires changes in the family system such as a change in coping strategies. Factors influencing people’s adaptation include severity of illness, unresolved strains, family functioning, resources and support from the community, family problem-solving and coping strategies. These factors interact with each other to determine the level of adaptation in the family. Therefore, McCubbin and McCubbin suggest that in studying families’ adaptation and coping, there is a need to look at the multi-factors influencing coping and adaptation, rather than studying one factor separately. The above may explain why some families cope and adapt better than others.

2.9 SUMMARY

This chapter provided a background understanding of issues affecting families’ caring for a relative with mental illness, including cultural care:

- The impact of caring for a relative with mental illness was documented in the literature; however, there was a lack of studies examining the experience of caregiving among families who come from diverse cultural and linguistic backgrounds. No studies of Egyptian families caring for a relative with mental illness living in Australia were identified.

- Caring for a person with mental illness could be overwhelming and distressing. Distress increased when the family migrated to another country. Immigration was found to be a precipitating factor in immigrants’ depression, due to loss of family and friends who are the main support systems, loss of status and issues related to resettlement in the hosting country.
• The literature revealed that there were similarities and differences between cultures. Differences were apparent in the use of space, touch, eye contact, use of food as a symbol of trust and in the way families view and cope with mental illness. People from the Middle East could attribute mental illness to the evil eye, use of magic, evil spirit possession. They were highly tolerant of the behaviours of the person with mental illness and against hospitalisation. They could resort to certain cultural practices such as the use of the zar cult, which may appear strange to Western cultures.

• Similarities between cultures were related to the families’ experience of stigma and blame. Families experienced overwhelming responsibilities, sacrifices and distress. Spirituality and social support played an important role in families’ coping among different cultures.

• Families of people with mental illness lacked adequate information about the nature of mental illness, the symptoms and prognosis of mental illness and how to manage the person with mental illness. It can be concluded that families need more support from mental health care professionals in terms of providing families with appropriate information and practical ways to manage their loved ones.

• The level of burden experienced by families varied. Factors such as carers’ age, gender, social class, social support, the gender, age, severity and chronicity of the person with mental illness, were found to contribute to this variability among carers’ ability to cope, adapt and survive. However, these issues remain controversial and more research is needed in this area, to explore other variables that may affect the carers’ coping, such as the personal strengths of carers.

2.10 RESEARCH AIMS

No studies of Egyptian immigrants caring for a relative with mental illness in Australia have been identified. This study aims to explore the experience of caring for a relative with mental illness in the Egyptian family living in Australia. The objectives of this
study were to reveal how Egyptian families survive the experience, the meaning of the experience to them, and to identify carers' needs in order to inform service provision, allocate resources and improve policy making related to immigrant-carers' needs. The following chapter provides a detailed description of the research process involved in the conduct of this study.
CHAPTER 3

THE RESEARCH PROCESS
Philosophy...

"makes it possible to see being in respect
to what it is in so far as it is being"
(Heidegger, 1958)

3.1 INTRODUCTION
This chapter provides a detailed description of all the steps taken to carry out this study: the choice of research design, the concepts drawn from hermeneutic phenomenology that contribute to the framework, the recruitment of participants, the method used to obtain data, and how the data were analysed and interpreted. This is followed by the procedures used to maintain rigour and issues of credibility of the study including ethical and cultural issues impacting on how the participants were approached, and the collection and interpretation of data.

3.2 RESEARCH DESIGN
Qualitative research methods are well suited to the kind of research that seeks understanding and deeper insight into the phenomena of interest, and are consistent with nursing values and practice. Both qualitative research methods and nursing are interested in subjectivity, shared experience, shared language, interrelatedness and in human interpretations (Munhall, 1982). Leininger (1985) suggests that qualitative research methods are important in generating knowledge for nurses, “Qualitative studies on cultural care of individuals, families, institutions, and world cultures are much needed. Qualitative research is the primary method to achieve this purpose and to gain new knowledge with which to understand our complex multicultural world” (p. 23).

Qualitative methods deal with the whole and parts of the particular issue under study, recognising that “the whole may be quite different than the sum of the parts” (Omery, 1983, p. 60), thus every aspect of a particular experience and the relationship between the parts and the whole are considered important.

The nature of this inquiry necessitated the use of a qualitative research method. This is because qualitative research is concerned with the totality of events and human beings. This approach is useful in revealing and discovering the meaning of a
particular experience of which little is known (Bockmon & Riemen, 1987). In this case, there is little known about the experience of caring for a mentally ill relative in the Egyptian family. The experience is one which involves very much the lived experience, therefore phenomenology provides an appropriate framework for the study.

3.3 PHILosophical Framework

3.3.1 Phenomenology

Phenomenology comes from the Greek word phenomenon meaning “the showing-itself-in-itself” (Heidegger, 1962, p. 54), and “logos” means reason (p. 55). “Phenomenology is about making manifest what one is ‘talking about’ in one’s discourse” (p. 56). It is about letting something be seen. Phenomenology seeks to understand the “nature of being” or the lived experience of beings, through the use of language (Bailey, 1997). The goal of phenomenology is “… to understand human beings not only to know how they are, but to understand them in order to know how to act” (Lynch-Sauer, 1985, p. 105).

The goal of phenomenology is to find the common meaning of shared practices in everyday lived experience (Gullickson, 1993). It is concerned about being-in-the-world. The world refers to people’s relationships, behaviours, beliefs, language and culture. It is based on the idea that all human consciousness is historical, sociocultural and expressed through language. Language is used to convey knowledge and understanding.

Phenomenology is used as a philosophy, an approach, and a research method (Ray, 1985). Phenomenology as a philosophy is valuable in that it can broaden nurses’ awareness of and understanding of the world. As an approach, it helps the nurse researcher to identify the participants’ needs through conversations and/or direct observations (Jasper, 1994). Phenomenology is used as a method to explore the meaning of a particular experience as it unfolds for the participants. It reveals the essences of a particular phenomenon, deepens and provides a fuller picture of the phenomenon under study (Spiegelberg, 1976). The researcher’s role is to generate knowledge that is a reflection of the participant’s perception of an immediate experience (Brockopp & Hastings-Tolsma, 1989). The only valid source of
information is the person who is living this particular experience. In this the researcher’s role is to understand, uncover, reflect and interpret the participant’s reality and the context in which this reality exists (Crotty, 1996) by “entering the lived world of the subject” (Bockmon & Riemen, 1987, p. 74).

3.3.1.1 Hermeneutic phenomenology

Hermeneutics, meaning interpretation, was originally used to interpret biblical texts. It was used to “reveal God’s message that it was believed the texts contained but that had become hidden” (Packer, 1985, p. 1082). Heideggerian/hermeneutic philosophy is ontological, concerned with human beings and their being in the world. It is concerned with the question “What does it mean to be a person?” (Koch, 1995, p. 832). Heidegger (1962) was concerned about the being of beings or the meaning of day-to-day experiences as lived by people and the possible meaning of their existence. For this reason, Heideggerian phenomenology is sometimes referred to as ‘existential phenomenology’ (Koch, 1995).

Heidegger takes the position that prior knowledge or presuppositions “are not to be eliminated or suspended, but are what constitute the possibility of intelligibility or meaning” (Ray, 1994, p. 120). This prior knowledge brings insight into a phenomenon, which comes from one’s past experiences (Spiegelberg, 1976). It is through the shared cultural and linguistic background between the researcher and participants that the researcher is able to have a pre-understanding, the fore-structure of understanding, of the participants’ behaviours, beliefs and practice (Leonard, 1994). This shared pre-understanding, the shared background familiarity allows for what Heidegger (1962) refers to as the ‘clearing’. It is the disclosedness of people’s worlds. It is through the ‘clearing’, which results from one’s pre-understanding, that interpretation is made possible.

According to Heidegger (1962), “the meaning of phenomenological description as a method lies in interpretation” (p. 61), which is why Heidegger’s philosophy is referred to as ‘philosophical hermeneutics’ (Gadamer, 1976). It is a way of making sense of everyday practices (Walters, 1995), a way of making sense of our existence and the meaning of being-in-the-world, “where new meanings can surface and better
interpretations achieved. The final interpretation is, however, only considered as tentative rather than as absolute or true” (Walters, 1995, p. 795).

In hermeneutics, interpretations and understandings depend on the researcher’s or reader’s perspective. One person may view an action as making sense, while another person may see the same thing and view it differently. In other words, “From one perspective an action has one meaning, from a different perspective it has another” (Packer, 1985, p. 1084). Furthermore, the time and the occasion of the same act can have a different meaning at a different time, so too the meaning and interpretation of the same experience. Thus, meaning is perspectival and can represent multiple realities. Ayres and Poirier (1996) elaborate, “Since each researcher is unique, and brings to analysis a unique aesthetic response, it is not surprising that multiple interpretations can emerge from different researchers’ encounters with the same artistic text” (p. 166). The difference in interpretation from researcher to researcher can be due to the theoretical and historical backgrounds, which researchers bring to the study (Leonard, 1989).

For Heidegger, truth refers to people’s realities. The existence of truth is essentially related to the existence of being. “Being-true as being-uncovering, is ... ontologically possible only on the basis of being-in-the-world ... which is the foundation for the primordial phenomenon of truth” (Heidegger, 1962, p. 261). Truth refers to disclosedness and discoveredness, which bring things out of concealment.

In Heidegger philosophy, the understanding of phenomena is dependent upon an appreciation of the importance of language, space and time in understanding a particular experience. This is because one’s language, space and time are important elements in revealing something about an entity. They provide a context in which a particular phenomenon is taking place. Without an understanding of the participants’ context, the stories would not be complete.

### 3.3.1.1 Language

Having the ability to express and reveal oneself through the use of language is what distinguishes human beings from other beings. Language is related to the disclosedness of people as being-in-the-world. It is a medium for communication.
Language, according to Heidegger, is not just words, but is “the way of speaking”, which also reflects the state of mind and the inner mood of being; hence it discloses something about the person (Heidegger, 1962, p. 205). He adds that “language ... is concerned that our speaking, in listening to the unspoken, corresponds to what is said. Thus, silence, too, which is often regarded as the source of speaking, is itself already a corresponding” (Heidegger, 1971, p. 131). This emphasises the importance of silence and the meaning behind it. Silence is seen not as a passive act, but an active act, in that silence has a voice that can speak and reveal something in a conversation.

When language is used to draw one’s attention to a problem, it is called ‘Articulation’. Relating this to the researcher-participant relationship, the participant allows the researcher to get into his/her world, by pointing out or ‘Articulating’ their stories, hence allowing the researcher to share the experience. This experience is also shared with others in the same situation. “What is shared is our being towards what has been pointed out - a being in which we see in common.... Others can share with the person making the assertion, even though [they are] not close enough for them to grasp and see it” (Heidegger, 1962, p. 197). The knowledge gained from disclosure allows others to gain access to what is real, that is to say, people’s stories and realities. Language is the articulation of reality (Heidegger, 1962). This concept is very important to the current study and fits well with the aim of the study, which is about the disclosure of participants’ realities through language.

3.3.1.1.2 Space

Space refers to the context of the study. The meaning of the practical activity of everyday life is interpreted within its context is what Heidegger refers to as referential totality. It is a way to understand an experience holistically, which includes paying attention to one’s feelings, thoughts and practices. These are shaped by culture and are related to a particular situation in which people find themselves. Space is not just a matter of measurements; rather, it is a reflection of a person’s real world. People at different stages of their life perceive space and distance differently because the space and distances in their life world are different. That is to say, people’s perception of space and distance changes with time, age or illness (Heidegger, 1962).
3.3.1.1.3  Time

People live in a temporal world, and are seen, understood and interpreted in terms of their temporality. Time gives meaning to one’s existence or being. Heidegger refers to time as historical. In historicity, the person is able to look back on past experiences in a way to recover from those past events. The past, present and future influence the way people experience a particular event, and reflect people’s lives as dynamic, changing over time, thus creating and existing in their own temporal contexts. People’s present reflects the state of being absorbed in everyday activities, the past is known and provides a basis for anticipating the future, which is known only as possibilities. In anticipating the future, people are experiencing a moment of vision, by seeing the present as part of its present being. This is done with acknowledgment to the past as something out of their control, but at the same time, as something which has influence on their present being (Heidegger, 1962).

The past, present and future are three interrelated aspects of a person’s existence, in that they influence each other. It is the past and the present that allows people to see possibilities for their existence by projecting to the future and seeing possibilities in the future. The significance of one’s past and future depends on the significance of the events which are taking place in at the present.

Heideggerian concepts of language, space and time and how these inform and impact on participants’ experiences will be dealt with in the data collection section of this chapter.

Heidegger’s hermeneutic has been used by many nurse researchers to explore and to bring to light the experiences of those whom they care for. The following are only a few examples of many others who have used Heidegger’s hermeneutic phenomenology as a research methodology for their studies. The findings of these studies have had implications for nursing practice, theory, research and education.

- Harvey (1993) used Heidegger’s phenomenology to discover the meanings that guide the practices of mothers during a high-risk perinatal experience. Findings of Harvey’s study led to the development of a new approach to advance nursing practice for a maternity clinical nurse specialist. It was
through listening to and understanding the women's experiences, which reflected their needs, that Harvey was able to develop a care plan to meet these women's needs. Thus her study and the approach used, helped to reveal the participants' needs, hence improving nursing practice.

- Gullickson (1993) used the Heideggerian hermeneutical analysis of the lived experience of persons with chronic illness, and provided important insights for all individuals interacting with persons living with chronic illness.

- Chesla (1989), in her study of parents' illness models of schizophrenia used hermeneutic phenomenology to describe the lived experience of schizophrenia as understood by parents caring for adult schizophrenic offspring in the community. Her study revealed the four models of illness in which the caregivers' understanding of everyday lived reality of schizophrenia present. As a result, parents' care patterns were shaped by these illness models. The study has implications for nurses in supporting families' efforts to care for their mentally ill member by trying to understand the meaning of the experience from the caregivers' point of view. Her study demonstrated the complexity and variability of care relations and caring practices for the mentally ill person.

All of the examples mentioned above have something new to say to nurses. These studies and many more have in common their focus on 'the meaning of experience'. They have brought to light the hidden meaning of people's experiences, through the process of understanding and interpreting these experiences, which otherwise would have been left unnoticed due to people's absorption in everyday life practices.

The following sections describe this study in detail and the implications of Heidegger's hermeneutics in the way data were collected, analysed and interpreted, and the steps taken by myself to achieve the rigour and credibility of the study.
3.4 The Study

3.4.1 Participants

The criteria for the selection of participants were being the caregiver of a relative with mental illness, of an Egyptian background, and being able to recall and reflect upon experiences. Seven Egyptian caregivers were involved in this study. Two members of only one family participated in this study. Initially the study aimed at interviewing more than one family member among all participants to examine the caregiving experience from different family members’ perspectives. However, due to the stigma associated with mental illness, people were reluctant to be involved. Another reason was that a number of carers were living in a nuclear family, where they were the only persons caring for their loved ones. There were no other adult family members who could participate in the study.

The nature of this study, which sought to provide the reader with a thick description of the subjective experiences of families caring for a relative with mental illness, did not require a large number of participants. Therefore, conducting the study with seven participants was sufficient for its purpose. The small number of participants does not mean that the information obtained lacks credibility. Sandelowski (1995) argues that a researcher working alone with limited resources can reduce the number of participants, but still produce credible and significant findings.

3.4.1.1 Access to participants

I faced some difficulty in accessing Egyptian families to participate in the study. There were several reasons for this difficulty. One was that I was looking for a heterogeneous/minority group of people that were hard to locate. The Egyptians were very reluctant to participate in a research study, probably because of their unfamiliarity and uncomfortableness with research, and their distrust of revealing personal information and discussing a highly stigmatised issue like mental illness to people outside the family. Gaining access to participants was through referral from psychiatrists, general practitioners, social workers and church.

The advertisement for the study included my name, my telephone number, my role, information on the aim of the study and the participants’ rights when involved in a research project (Appendix ).
3.4.2 Data Collection

Hermeneutic phenomenology provided the framework for collecting data for the study. In phenomenology, the interview is used as the preferred method for data collection. The purpose of the interview “... is to gather descriptions of the life-world of the interviewee with the intention of interpreting the meaning of the described phenomena” (Kvale, 1997, p. 149). Hence, the purpose of using this method fits with the purpose of the philosophical framework guiding the study. This methodology, as mentioned earlier, focuses on the meaning and interpretation of people’s experiences.

The interviews allowed the participants to talk about their experiences while focusing on the research question. The interviews were more like a conversation than formal interviews, in that the participants’ worlds started to unfold. Leading questions were only asked to elicit information and to clarify any issues being discussed during the interview, thus enhancing the reliability of the interviews rather than reducing it.

Kvale (1994) asserts that

The interview is a conversation where the data arise in an interpersonal relationship, co-authored and co-produced by the interviewer. The decisive issue then is not whether to lead or not to lead, but where the interview questions lead, whether they lead in important directions, yielding new and worthwhile knowledge (p. 156).

Questions were kept to a minimum for clarification and better understanding of the issues discussed with participants.

- The focal question was “Can you tell me what is it like to be caring for a relative with mental illness?”
- Probes were “Can you tell me more about ...”, “What do you mean by ...”? ”

The above questions aimed at encouraging participants to talk openly about their experiences. All the participants were volunteers and good informants. They talked about various issues related to the caregiving experience without further questioning. The participants were comfortable in talking about their experiences with all the ups and downs, the concerns and problems they faced in caring for their mentally ill
relative, which in turn made me comfortable too, and eased the process of data collection. The carers' comfort in talking with me reflected their need for someone they could talk to and someone willing to listen to their concerns and needs without being judgmental. The participants provided an excellent account of their experiences, which was reflected in the issues they discussed. They brought to light their everyday practical knowledge, hence allowing access to practical worlds.

The time to conduct the interviews was set for the convenience of both the participants and myself. I rang the families the day before the interview to confirm the time of the interviews. During the interview, attention was given to both verbal and non-verbal communication. This is because communication is not just an exchange of information between people, but is how the information is presented. This includes the tone of voice, the way people dress, where and when the interactions occur. More than 90% of the effect of communication on people relies on non-verbal cues (Newman, 1998). It is also noted that the Egyptian culture is a “high-context culture”, where people rely more on non-verbal communication such as body language, thus relying less on verbal communication. Accordingly, the researcher paid careful attention to this important factor in collecting, analysing and interpreting the data. In the context of this study, some participants were contacted via telephone to clarify and to check content. Data collection took 6 months post gaining Ethics’ Committee approval to conduct the study.

The following are other cultural issues, which were considered in the interview to enhance the quality of the obtained data, and in interpreting the data. These examples are only mentioned briefly here, as they were discussed in more depth in the literature review chapter. An example is the awareness of proximity when interacting with the participants. Egyptians prefer to be as close as half a metre. In addition, the use of touch was used appropriately especially when interviewing the opposite sex. Furthermore, the use of eye contact that is considered culturally appropriate was also observed.

Other issues concerning the conduct of the interviews included maintaining good/active listening to the participants' stories, understanding the stories from the
participants’ point of view, being non-judgmental, being attentive to non-verbal cues, and paraphrasing to avoid any misinterpretation and to show empathy.

Egyptian people’s use of time also differs from other cultures. The participants may cancel or come late for the interview; this can happen when something more important comes up and cannot be postponed. Then other arrangements to conduct the interview need to be made (Lipson & Meleis, 1983). Another feature that characterises the Egyptians is that they can repeat the same information again and again to emphasize an idea or give examples to express a point. Furthermore, they do not get to the point straightaway, since this is considered as being tactless and sometimes rude. This was considered when deciding about the length of the interviews. They were planned to be about one hour; however, the interviews lasted longer after considering the factor mentioned above. In fact, the majority of the interviews lasted between 1 ½ - 3 hours. All interviews were audio-taped. Participants were given the chance to choose the place where the interviews were conducted and which was convenient to them. All interviews were conducted in a place that helped participants feel relaxed and able to express and reflect upon their experiences without many interruptions. Notes and a reflective journal were used to describe the context, interactions with the participants, my feelings and thoughts from data collection to the presentation of interpretation. These were not part of the data, but used by myself in constructing the study.

For data collection techniques to fit with the methodology used, the emphasis was on language, time and space. Participants were encouraged to express their feelings and thoughts in their own language, to talk about time in terms of their past, present and future, as well as exploring issues related to participants’ use and understanding of space.

3.4.2.1 Language

The interviews were conducted using the participants’ native language, the Arabic language. These were then translated into English by myself as I am fluent in both Arabic and English. This was done to ensure that the participants comprehended and were able to express their feelings and thoughts freely. Both the participants and myself shared the same linguistic and cultural background. My background and prior
understanding of the Egyptian culture was brought into the study. Using the participants’ language was important, when language is considered as part of and a reflection of one’s culture and the loss of one’s language can lead to the loss of the culture itself (Benner, 1994). Accordingly, the researcher ensured that the participants preserved their language, thus their culture, and used the participants’ native language, which was Arabic. It has been emphasised that the larger the distance between researcher and participants’ background, the greater the problems of mutual understanding and interpretation (Benner, 1994). This is because effective communication is made possible through a shared background of understanding (Dreyfus, 1991). Sharing the participants’ language and culture made communication and expression easier during the interviews, and in interpreting the findings, which were based on mutual understanding.

Additionally, my background of living in Australia for 13 years, doing a bachelor of arts-major in English, in which translation was part of the course, studying in an English school earlier in my life, all contributed to my ability to accurately interpret and translate from Arabic to English and vice versa. As a result, I was able to reflect the participants’ experience in the most accurate way (in English) to readers who do not share the linguistic and cultural background of the participants, thus bridging the gap between the two cultures and overcoming the language barrier that would otherwise prevent people becoming aware of the other culture.

Use of interpreters was avoided; it was not necessary as I am bilingual, and the presence of a person other than the participant and myself during the interviews would have caused discomfort to the participants. Added to this, the process of interpretation, such as asking a question or elaborating on some issues, then interpreting back to the participant, would have interrupted the flow of ideas which the participants wanted to discuss without being interrupted. It would have distracted the participants, and impeded the quality of data obtained rather than enhancing it. A sample of translated text was checked for authenticity by a professional interpreter.

Consistent with the aim of phenomenological methodology, which is to find meaning in the phenomena under study, the interviews were read several times and analysed in Arabic, then translated and transcribed in English only with the aim of conveying
meaning rather than translating word by word, rendering the transcribed text meaningless. Thus verbatim translation was avoided, keeping in mind that the main aim of the study and its methodological underpinning was to generate the meaning of the experience.

3.4.2.2 Time

According to Heidegger (1962), time gives meaning to one’s existence or being. People’s past, present and future influence the way people experience a particular event. This reflects that people’s being is dynamic, and changes over time. People thus create and exist within their own temporal contexts. People live in a temporal world or lived time. This lived or present time is influenced by one’s past, which includes personal and cultural practices. Therefore, participants were asked to talk about their life before, during and after the experience, which also reflected the temporality of human existence/being.

3.4.2.3 Space

Consistent with the philosophical underpinnings of this study, which emphasise the importance of one’s space, participants were encouraged to talk about their space and the meaning attached to it in order to provide a holistic view of the experience and to contextualize it. This provided an understanding of how the participants use space and how things are viewed and experienced in terms of space. Heidegger (1962) asserts that when people are situated in the same place, they may share similar experiences and that distance is not just a matter of measurements, it is rather a reflection of people’s real world. In this sense, space refers to the context of the study. Trying to understand the experience in isolation of its context will result in ambiguity (Walters, 1995). Heidegger (1962) believes that the context of an experience provides a holistic view, understanding and interpretation of this experience. The meaning of practical activity in everyday life, feelings and thoughts cannot be understood and interpreted independently of the type of situation which gives rise to them, and so can be evaluated in terms of its appropriateness to the context.

Accordingly, participants were encouraged to talk about their feelings, thoughts, everyday activities, ways of living and coping, and the availability of/lack of support.
system. Participants talked about their experiences before and after immigration, the experience of leaving their own cultural place, which they shared with friends and families and the meaning attached to this space. Participants talked about the new space they occupied in Australia, which differed from that in their country of origin. Space was an important aspect in the caregiving experience and impacted on the way families coped with the caregiving experience as revealed in the analysis chapter.

3.4.3 Analysis and Interpretation

The following methods of analysis were chosen for their suitability and fittingness with the aim and purpose of this study and its methodological underpinnings. In analysing the data, the focus was on preserving the uniqueness of each lived experience, and understanding and finding meaning in the experience itself. Analysing the participants’ stories did not end at this point, because hermeneutic phenomenology took me a further step in the analysis process, which involved interpretation of data.

Data analysis started from the beginning of the data collection. I listened to the audio-taped interviews several times in Arabic to get some sense of each participant’s story. The interviews were then transcribed in English for further analysis and convenience of examination. Transcription has been described as “a technique that involves the selective preservation of elements of the research interview” (Sandelowski, 1995, p. 373). Therefore, in translating and transcribing the interviews, the focus was on the essential elements of the interviews, rather than transcribing word by word, which could impede understanding and the analysis process. After all interviews were translated and transcribed, I read the transcribed English text over and over again while listening to the original interviews, which were in Arabic, to ensure that I had captured the meaning behind the transcribed text and to ensure that I had not missed out on any important point during the process of translating and transcribing. Sandelowski (1995) has suggested that proofing and checking the transcript against the audio-taped interviews is in itself a kind of analysis.

Consultation with professional interpreters and translators confirmed that it is not possible at all to translate languages word by word and get the same or intended meaning; some meaning will be lost if the interviews are translated and transcribed.
verbatim. Meaning in the hermeneutical sense is captured from within the text (Allen & Jensen, 1990; Ray, 1998). In this approach, the interest is not in what the text describes (explanation) but what the text discloses (understanding). It is this disclosure of the text which allows the researcher or reader to move from a superficial to a deeper understanding of the meaning of the text (Allen & Jensen, 1990).

Each interview was read as a whole, and analysed separately, then all interviews were compared to each other to get a whole sense of all interviews, and to find any similarities and/or differences. Any similarities and/or differences in the themes identified were presented as accurately and honestly as possible. “Themes are large units of analysis derived from patterns which can explain multiple aspects of human behavior” (Carter, 1985, p. 61). In this study, themes were presented to reflect the participants’ experience and their world, and constitute what is real in being-in-the-world and the meaning of one’s existence. This is consistent with the philosophical underpinnings guiding this study, which focuses on the meaning of a particular experience.

The identified themes were then evaluated and compared to the original data. Themes were also compared to each other to find out any differences and/or relatedness among them. This was done to provide clarity, and to pull the separate parts of the experience together, to come up with an accurate meaning of the lived experience of families caring for a person with mental illness, as a whole. These methods of analysis involved elements of hermeneutic analysis, based on the “hermeneutic circle”. Understanding and interpretation are two important concepts in the hermeneutic circle. This process opened up a new world of understanding the participants’ stories.

Participants were viewed as being able to interpret and reflect upon their experiences. However, these understandings and interpretation were not made fully explicit. Therefore, my role was to explore the underlying description of the stories and go beyond what was directly given, by looking at clues for meanings, which were not given, or not explicitly given, as suggested by Spiegelberg (1976). The validity of a researcher’s interpretation to the participants’ account of the experience is achieved when the participants are able to say that the researcher was able to put into words
what they have always known, but did not know how to express verbally (Dreyfus, 1991).

Interpretation and understanding are interrelated to the point that they co-exist. Without interpretation there is no understanding, and without understanding there is no interpretation. It is this interpretative understanding which is referred to as the "hermeneutic circle". "In interpretation, understanding does not become something different. It becomes itself" (Heidegger, 1962, p. 188). This understanding and interpretation leads to more and better understanding of being or experience. Using Heidegger's words (1962), "understanding that is to contribute to understanding, must already understand what is to be interpreted" (p. 82). This is the pre-ontological understanding of interpretation.

The hermeneutic circle is referred to as an arc (Packer & Addison, 1989). There is a forward arc of projecting and seeing possibilities. Projecting is what has already been understood in the background practices, which makes seeing possibilities possible (Dreyfus, 1991). By relating this to the hermeneutic circle, the researcher's point of view makes understanding possible through the shared background understanding. This refers to the researcher's pre-understanding of the issue under study, which is influenced by the person's background. The reverse arc is of uncovering, which allows for a better understanding and interpretation of what has been already understood. This arc provides for evaluating the interpretive account. The processes involved in the hermeneutic circle presented here are in the form of a forward and reverse arc, which are a representation of interpretation and evaluation of an interpretive account.

In the process of interpreting the participants' experience, I moved backwards and forwards, and between the whole and parts in my interpretation of the experience. In analysing the stories as a whole, I gained new understanding, which was then used to examine the parts of the whole to discover new important details of the experience. This in turn led me to re-examine the whole in the light of my new understandings and the insight gained from examining the parts and so on. "Thus the interpretation process has no clear termination" (Leonard, 1994, p. 57). The above steps continued until the interpretation process or 'circle' brought about the deepest understanding of
the story being told. This new interpretation led to further new understanding and so on - the hermeneutic circle. Consequently, “we are dealing with interpretations and interpretations of interpretations” (Koch, 1995, p. 831).

The following section provides a detailed description of the steps taken to reflect the trustworthiness of the study methods and findings.

3.5 ACHIEVING RIGOUR

In hermeneutic phenomenology, the researcher is considered a participant in the study. Therefore, I brought into this study my experience as a psychiatric nurse working with clients and families who come from different cultural backgrounds, as well as my past experiences as an Egyptian. As a researcher, I kept in mind Heidegger’s hermeneutical underpinnings and I was consciously aware of and acknowledged my background understanding of the Egyptian culture. Sharing the same linguistic and cultural background with the participants enabled me to establish and maintain rapport and trust with them throughout the research process. My prior understanding enabled me to anticipate certain behaviours that would be considered either culturally acceptable or not, especially during the interview process, such as the Egyptians’ attitudes to space, time, silence, touch, gender and religious issues. This influenced the way the interview data were interpreted. I allowed this prior understanding of the Egyptian culture to have a place in the study to enhance the processes and outcomes of the research undertaken. Plager (1994) argued that “the forestructure of understanding gives some anticipation of the event but does not permit exact prediction” (p. 76), thus encouraging the researcher to be open to and be receptive to new understandings and interpretations revealed by the text.

I also viewed the participants as having the ability to self-interpret, hence valuing and respecting their account of the experience and the insight gained from recalling and reflecting on their caregiving role. This included respecting their attitudes, beliefs and values related to their experience as caregivers. Acknowledging and being aware of my background understanding of the study and at the same time respecting the participants’ experiences and being as open as possible to what was happening in the study, opened the possibility for both the participant and myself to gain new understandings of self and others.
Hermeneutic analysis is concerned about the way data are understood and interpreted. In the current study, I used a circular process of interpreting and understanding, which occurred by moving backwards and forwards within the text, reading the text as a whole and paying attention to the details of the parts. I continued to move backwards and forwards between what was already known through my fore structure and what the text revealed. I remained close to the text and by constantly checking that the interpretive account agreed with what the text revealed, I thus attempted to overcome any misinterpretation of findings. Interpretation is the essential element in hermeneutic phenomenology. This is because hermeneutic phenomenology is not only about finding meaning and understanding, but also about being able to interpret life events.

Leonard (1994) suggested the use of exemplars to enhance the interpretive analysis of the data. An exemplar is “a strong instance of a particularly meaningful transaction, intention, or capacity” (Benner, 1985, p. 10). In the current study, it was from the analysis and illustration of specific incidents of the participants’ experience and the participants’ response to them, including their concerns and behaviours, that exemplars were identified. Chesla (1994) suggested that “caring practices are best described in exemplary stories of care that demonstrate the complex relations between the situational constraints and demands, and caregiver concerns and actions” (p. 171). Therefore, specific exemplars of incidents where the caregivers experienced difficulty in caring for their relative with mental illness and how they coped with it are presented.

I attempted to provide a meaningful interpretation of the text, which represents the participants’ stories, but kept in mind that people’s experience can never be made completely explicit. The outcome of interpretive research can lead to multiple interpretations of meaning, which does not mean that these interpretations are invalid or inaccurate. It is in this kind of research “that there can always be another, deeper and perhaps more persuasive, interpretation of a phenomena” (Leonard, 1994, p. 61).

The credibility in qualitative research is about the truthfulness of the description of the phenomenon under study (Beck, 1993). The concept of truth as unconcealment,
uncovering or illumination of an experience leads to a deeper understanding of the meaning of an experience (Heidegger, 1972). It is through the text that people's worlds unfold. This is what Burns (1989) refers to as "descriptive vividness" (p. 48).

To convey credibility of the study, a full, clear, true description of the social context of the study is provided, so that the reader can have a sense of, live, and relate to the experience of the participants. In order to achieve this, direct quotes from the text/transcribed data are used as illustrations of the themes and meanings, which reflect the carers' experience. Quotes are used to "support [researcher] claims, illustrate ideas, illuminate experience, evoke emotion, and provoke response" (Sandelowski, 1994, p. 479).

Credibility is also achieved when the researcher can recognize that his or her description or interpretation is correct because the reflective process awakens an inner moral impulse. This has been referred to as the "phenomenological nod" (Van Manen, 1990, p. 27). This means that when people read the descriptions and interpretations of an experience, they are able to relate to this experience. This will help the reader to have new insights about themselves as well as others around them (Glesne & Peshkin, 1992). Guignon (1983) explained Heidegger's 'measure of truth' involved in interpreting research findings as follows:

> The measure of truth...is not whether it offers us a correct representation of who and what we are; [rather it] lies in the way our lives are enriched and deepened through these descriptions ... truth is envisaged as the emergence of a clearing or opening that releases entities from hiddenness ... the description is measured not by criteria of correctness, but by criteria pertaining to its consequences for our lives (p. 230).

Koch (1994) suggested the use of a decision trail, which consists of credibility, transferability, and dependability, to achieve truthworthiness and rigour in qualitative research. Rigour is achieved through the process of auditability. Sandelowski (1986) offered 12 steps to ensure auditability, which require the researcher to address the following: how the researcher became interested in the subject matter of the study; how the researcher views the thing studied, the specific purpose (s) of the study, how
subjects or pieces of evidence came to be included in the study and how they were approached; the impact the subjects or evidence and the researcher(s) had on each other; how the data were collected; how long data collection lasted; the nature of the setting(s) in which data were collected; how the data were reduced or transformed for analysis, interpretation, and presentation; how various elements of the data were weighted; the inclusiveness and exclusiveness of the categories developed to contain the data; and the specific techniques used to determine the truth value and applicability of the data (pp. 34-35). Accordingly, every step taken in this study was described accurately, and the reason for it explained clearly. This was done to achieve auditability.

Providing the final report/interpretations was voluntary, that is, participants were offered the final report to read if and only if they wished to do so. This was done to protect the participants who did not wish to read or go through the process of recalling the experience as it might trigger distressful memories or feelings. However, the participants involved in this study were curious to know the results of the study and how the findings could benefit them. They were pleased to know that they were not the only ones who were going through the same situations. I also explained to the participants that when the study had been fully finished, they would be provided with the end product of the study in recognition of all the effort they had put into the study and their contribution to it. I did this in order to give them a sense of being actively involved in the research process. Furthermore, it was my wish to provide them with the end product as I owed it to them; it would be because of their input into the study that I finished it successfully and truthfully. It was also a way to provide reassurance regarding maintaining their anonymity in the final report.

3.6 Ethical Considerations
The University of Western Sydney Ethics Committee’s approval was obtained prior to conducting the study. Informed consent from all participants was obtained, which meant that all participants voluntarily participated in the study without any pressure or threats to them. Verbal consent was obtained from all participants. For cultural reasons, written consent was not obtained as this could have been misinterpreted as being a lack of trust on my part; written approval would indicate that I did not trust their verbal agreement to participate in the study. A verbal consent was adequate and
sufficient and conveyed that I respected and trusted them when they verbally agreed to take part in the study. It meant that I respected and trusted their word. Reassurance about the confidentiality was given to all participants over the phone and prior to the actual interview. An information sheet including all the necessary information regarding the study and the participants' rights was given to all participants. A full explanation regarding the aims and nature of the study were also explained in the information sheet. An explanation of the potential benefits of the study was provided (Appendix A).

Participants were informed about their rights to refuse to participate and/or to withdraw from the study. In addition, participants were informed about the possibility of experiencing some emotional discomfort during the interview, which might result from sharing their feelings about the care their loved one had received, and in asking about their personal experiences. The possibility that the interview might evoke different reactions such as tears, anger and the like were taken into account. Therefore, immediate and appropriate emotional support was offered. For example, I would stop the interview for a while to allow the participants to gather their thoughts and relax. Participants were aware of the availability of an independent counsellor if needed; however, this counsellor was not needed.

The participants' cultural backgrounds, beliefs, values and attitudes were respected throughout the study. Participants were viewed as 'rational' people who have the ability to self-interpret, which is a moral, ethical and hermeneutic perspective. A trusting relationship was established between the participants and myself, based on respect and honesty. I listened to the participants' feelings and thoughts in a non-judgmental way. Reassurance was provided to participants regarding their privacy, confidentiality, and anonymity throughout the study by using pseudonyms throughout the research process. The audio-tapes and the transcribed data were locked in a safe place to ensure that no one would have access to this confidential data. Honesty in interpreting the results was maintained. At the end of each interview the participants were thanked for taking part in the study.

Chapter 3 – The Research Process
CHAPTER 4

THE EXPERIENCE
THE EXPERIENCE

He is able to get across to me in as much as I am ...
capable of allowing myself to be led by the flow of talk
toward a new state of knowledge
Merleau-Ponty, 1962, p. 143

4.1 INTRODUCTION
This chapter introduces the participants’ stories, feelings and thoughts. Each participant’s background and the context surrounding their stories is presented to allow the reader to contextualize the stories. This is followed by the thematic analysis of the transcripts and the presentation of extracts from the participants’ conversations.

4.2 INTRODUCING THE PARTICIPANTS

4.2.1 Peter George
Peter and his family migrated to Australia in 1997. Peter was 32 years old and his wife, Jasmine, was 29. Peter and his wife had three children; the eldest child was seven years old and the youngest was two years old. When Peter immigrated to Australia with his family, he had dreams of settling and finding decent employment in the new country. He used to work as an accountant, and his wife had been working as a registered nurse for many years in Egypt and was accepted to practise in Australia. He was happily married for ten years until his wife had an accident, which left her paralyzed and depressed. He was the primary and only caregiver for his wife, who was mentally and physically ill, and his three little children.

4.2.2 Farah Mina
Farah and her family immigrated to Australia in 1972. She had two sons and a daughter. Farah was 70 years old and was the primary caregiver to her 43 years old son (Samir) who was diagnosed with schizophrenia at the age of nineteen. Farah’s husband was a very wealthy person, who was a general in the army. They owned land, property and two large yachts, running their own business and owning three large petrol stations in Egypt. After Samir’s diagnosis, Farah’s husband became distressed and for some reason, on which Farah did not elaborate, they lost all their wealth. Farah’s husband died ten years ago, leaving the family without any financial
support. At the time of data collection, Farah, was living with her youngest son in poor housing condition.

4.2.3 Sarah Mina
Sarah was the only daughter of Farah and Samir’s sister. She was 45 years of age, and lived in a flat with her three young boys. She had been living with Samir for years before she got married and left the family home. She did not have a job but relied on social security benefits to support her children after her divorce four years ago. One of the reasons for her divorce was that she and her husband were constantly arguing about Samir’s mental illness. She had a very strong relationship with Samir, which was disrupted after the illness. Samir’s illness also changed her relationship with her mother, as well as with her former husband.

4.2.4 Sam Emile
Sam was born in Australia of Egyptian parents. He was the only brother of his sister Fifi, who was diagnosed with schizophrenia and epilepsy. He was 27 years old and had been married for the past two years. Before that, he lived with his sister in the family home, where he used to look after her from the time, she was 17 and he was 19 years old. He was a scientist whose opinion and thoughts were a bit different from his parents in terms of how they viewed mental illness. Having a sister with mental illness was a source of embarrassment and disruption in his social life, including with friends and with his wife, especially during their engagement period, as his sister used to get jealous of his wife and cause trouble to them.

4.2.5 Rhonda Farouk
Rhonda was 36 years of age and had been caring for her depressed husband for the past three years after he lost his job. She was a mother of four children; the oldest was 15 and the youngest was one year old. She had been living in Australia for the past 11 years. Rhonda was a Christian before she met Mohammed who was a Muslim. Her parents were against this marriage. She did not want to tell her family that her husband was mentally ill, for fear they might blame her for changing her religion and marrying him against their will. She was devoted to her family and to the care of her husband. However, Mohammed married another woman while he was still married to Rhonda. El-Islam allows men to marry up to four women at a time.
Mohammed's second marriage was devastating for Rhonda as she did not expect him to do this after what she had endured for him. Besides he became more negligent towards her and the children.

4.2.6 Andrew Silver

Andrew was 30 years old and was the primary caregiver for his wife, Dina, who had been diagnosed with bipolar disorder 3 years before. They had been married for four years and they had no children. Andrew was an accountant who immigrated to Australia with his family when he was 17 years old. Andrew kept the fact that his wife was mentally ill hidden even from his parents for fear that they would try to turn him against his wife or ask him to leave her and get married to a different woman. Due to his secrecy about his wife’s mental illness, Andrew was left to care for his wife and cope on his own.

4.2.7 Rosa Morcus

Rosa was 26 years old. Her father had developed paranoid schizophrenia ten years ago, but had only been diagnosed 4 years ago. Before that he had been exhibiting all the signs and symptoms of mental illness but the family was highly tolerant of his behaviour and he himself would not go to a doctor in any case. Rosa had immigrated to Australia four years ago with her parents and her only sister, who was now 17 years old. She was in her final year of studying medicine in Egypt when her father decided to come to Australia to be with the rest of his family. She was currently studying dentistry. Her father’s diagnosis was not a shock for Rosa; she stated that her father had been always like that, it was his nature, his character/personality and she and her sister grew up to find their father like that. They had learned to live with it, but they could not cope well.

The above section has introduced the participants’ background to allow the reader to make connections, understand and contextualize the experience. The following extracts expose the essential nature of the phenomena of caregiving and surviving, to allow the reader to participate in analysing and finding meaning in the participants’ conversations. It is through these extracts that the reader may be able to interpret what is familiar and common in new ways.
The five major themes that uncovered ways of knowing and understanding the caregivers’ experiences and how they managed to survive despite of everything were: *Why did this happen? How do I protect my loved ones? What has it done to ME? What has it done to US? How do I survive?* The final thematic structure is shown in table 1, which depicts the major themes, minor themes and sub-themes and their relationships.

<table>
<thead>
<tr>
<th>MAJOR THEMES</th>
<th>MINOR THEMES</th>
<th>SUB-THEMES</th>
</tr>
</thead>
</table>
| **Why did it happen?**| Being Shocked                       | • Disbelief
                                             • Not taking it seriously                                                   |
|                       | Blaming                             | • God
                                             • Self
                                             • Others
                                             • The person with mental illness
                                             • The medication
                                             • The evil eye
                                             • Magic
                                             • Evil spirit possession                                                   |
| **How do I protect my loved ones?** | Protecting at home                  | • Out of love and duty
                                             • Religious beliefs, family traditions and upbringing                      |
|                       | Protecting at hospital              | • Satisfaction/dissatisfaction with the health care services                |
|                       | Being drained                       | • Physically drained
                                             • Emotionally drained
                                             • Financial difficulties                                                   |
| **What has it done to ME?** | Sacrificing my own dreams, freedom and future |                                                                            |
|                       | Losing my identity/role             |                                                                            |
| **What has it done to US?** | Living in isolation                 | • Being alone and lonely                                                    |
|                       | Change in the relationships with friends and family | • Disruption between husband and wife
                                             • Disruption between siblings
                                             • Disruption between siblings and parents                                  |
| **How do I survive?** | Living in hope                      | • Hope for a miracle                                                        |
|                       | Remembering good times              |                                                                            |
|                       | Enduring and accepting the realities | • Comparing one’s life to others                                            |
|                       | Seeking professional help            |                                                                            |

Table 1: Themes and sub-themes
4.3 THE STORIES UNFOLD

4.3.1 Why Did It Happen?
Families wondered why this happened to them. They were shocked by the diagnosis. They blamed God, self, others, the person with mental illness, the medication, the evil eye, magic and evil spirit possession.

4.3.1.1 Being shocked
Feelings of shock and disbelief were reported by the caregivers when they knew that their loved ones were mentally ill. Some families thought that it was a matter of time that the person with mental illness would get better. Others were shocked with the diagnosis. Peter viewed depression as follows:

> When the doctor told me that my wife has major depression, I didn’t take it seriously ... depressed! So what? Everyone feels depressed from time to time ... we never heard back in Egypt that if a person is depressed, they call him mentally ill ... but after living in this for two years, I realized how serious it is and how it affected our lives ... I was shocked about this realization, and the fact that my wife is mentally ill ... Everything was overwhelming, I could not believe what was happening to my family. One day everything was ok and suddenly things have changed.

Farah, Sarah, Rhonda and Rosa shared thoughts that were similar to Peter’s. Sarah reported I feel overwhelmed by what has happened, how the years change people, sometimes, I still cannot believe what had happened to us. Everything happened suddenly, and unexpectedly. Farah wondered why her son ended up being like that. She contemplated, saying it is a big loss, he (her son) was the perfect child a mother would wish to have, why did this happen to us?

4.3.1.2 Blaming
‘Blaming’ was an issue that was raised by all participants. However, blame took different forms. Blame was directed towards God, the self, the parents, the person with mental illness, the medication, the evil eye, magic and evil spirit possession.
The experience of having a mentally ill relative in the family affected them spiritually. All participants questioned God for allowing that to happen. They blamed God for the changes that happened to their lives as a result of having a relative with mental illness. Andrew questioned God’s love and blamed Him for his sufferings *Why did You do this to me? What did I do to deserve this? Why didn’t You prevent this happening to me? You have the power in Your hands to change things, so why don’t You want to do something? Is that what You want for me – to suffer?*

The parents of mentally ill children blamed themselves rather than blaming their ill children. They felt that they might have done something that contributed to their son’s or daughter’s condition. Farah, the mother of a schizophrenic son, stated that her son was constantly blaming his parents for his mental illness. After sending her son to a psychiatric hospital when his behavior became unmanageable, Farah stated: *I kept blaming myself for doing this to my own son...How could I do this? I should sympathize with him.*

Families reported that their ill relative accused and blamed them for their illness. Farah described how Samir blamed them (his parents) for his illness, *you are the cause of my illness, since I was ten years old, I have never felt that I have grown up one day older than this age, as if I am still only 10 years old.*

Similarly, siblings of the person with mental illness blamed the parents. Sarah blamed her parents for spoiling her brother and contributing to his mental illness:

*Honestly, I blame mum and dad, they used to treat him in a special way ... if he couldn’t finish his homework, dad would finish it for him so that he wouldn’t be in trouble at school, mum would bring him food in bed every day, all meals, she wouldn’t let him clean his room, she would do it herself, he was treated like a prince ... if he did something bad, no one would tell him to stop or tell him this is wrong ... their love for him was damaging and it destroyed him.*

Similarly, Sam was angry with his parents, particularly his mother, who refused to keep his sister in hospital or rehabilitation and he blamed and accused them for the deterioration of her mental state.
I told them she needs to go to hospital, the people there will take care of her, dad nodded his head, he was not sure, he wasn’t against the idea at the same time he didn’t approve of it completely, but it was mum who was totally against the idea and was very angry and defensive.

Some families blamed the ill person for the changes that happened in their lives as a result of this person. They blamed them for making them give up many things and for having to make sacrifices that they were not happy about. They did it out of duty or obligation. Peter expressed how his wife’s mental illness changed his life:

She is the cause of my sufferings and how I feel now. She is the one to be blamed for my misery. I had many hopes that I dreamed of achieving, now I cannot achieve anything, I do not have a stable life ... I feel anxious and stressed out all time, it is her fault that I turned against God.

Families and their mentally ill relatives blamed the medication for worsening the condition of their loved ones. Farah stated:

he (her son) wasn’t too bad before he went to the hospital. He wasn’t hearing voices, but they gave him lots of medication, which made him hear voices and made him more aggressive and angry than before ... the medication he took for many years deteriorated him and worsened his condition.

Rosa believed that the medication did not do much for her father:

we’ve tolerated his behaviour for the last 10-12 years without any support from anyone, no medication ... what can the medication do anyway? It just relaxes him, they are not persistent enough, it does not cure.

Some caregivers blamed the evil eye and magic. They attributed mental illness to the envy of other people, and the use of magic by their enemies to cause mental illness to their loved ones as in Sarah’s and Farah’s stories. Other families attributed mental illness to spirit possessions/evil spirits, as in Sonia’s and Farah’s case.
The voices he is hearing and talking to are the "Afareet" [which are the evil spirits in English], not mental illness. I took him to a priest to find out what is wrong with my son and the priest said that he is possessed and required a prayer of three days to perform an exorcism, but he refused to attend to this.

Farah stressed her belief in evil spirits and said that one day she asked the priest to visit her son during his stay in the psychiatric hospital, and to pray for him. The priest was holding a cross in his hand, and when he walked by other mentally ill people, they all collapsed on the floor because they (the evil spirits) were scared of the power of the cross. She added,

I saw them talking to themselves, and so is my son, they are not hearing voices, this is not madness, and they are talking to the evil spirits. These are ‘afareet’. I swear it is ‘afareet’. This is mentioned in the Bible, where Jesus used to cure those who were thought to be mad, but they were actually possessed by evil spirits ‘afareet’, and people considered them mad.

The experience of diagnosis left families wondering why it was happening to them. They felt shocked by the diagnosis of mental illness and they found it hard to believe that this was happening to them. The families’ disbelief in mental illness resulted in families blaming God, the evil eye, magic used by other people to harm the family and evil spirit possession. Families also blamed one another. Siblings of the person with mental illness put the blame on the parents, parents and carers blamed themselves, and they blamed the medication for either causing mental illness or worsening the mental state of their loved ones.

4.3.2 How Do I Protect My Loved Ones?

4.3.2.1 Protecting at home

Families’ protection of their loved ones was out of love, out of duty, out of love and duty, because of their traditions, family upbringing and religious beliefs. Rhonda, out of pure love, protected her depressed husband: Doctors prescribe medication, I have nothing to offer except my love. I loved and still love my husband, and I will stand by him no matter what. Other families protected their ill relative out of obligation and
duty, because they felt that they owed it to the mentally ill relative. However, they were not totally satisfied with this experience, because they felt that they did not have a choice and there was no way out. Peter stated: *I do not want to be selfish, I do not want to complicate things by leaving her (his mentally ill wife). I feel I owe it to her to stay and care for her, after the many years she looked after me. How can I leave her now?*

Other participants had a mix of feelings. They mentioned that with the sense of responsibility and duty, protecting their relative was also accompanied by a feeling of love and a sense of belonging. Sam’s protection for his sister was a result of a mix of duty and love, but again the sense of having to do it/duty was not an easy thing to deal with.

*It is always love, you can’t hold that, I love my sister a lot but at the same time I am down to have to do it no matter what ... I think it is more love, but also even if it was not love, it is out of duty. It’s been always a burden, which you have to get used to, she is family so I have to do it, you have to live with it, if you can’t that’s bad luck. When mum and dad are at work, I have to be home with her ... she has to be watched 24 hours a day.*

Families reported that they stood by their mentally ill relative due to their religious beliefs and the way their family raised them. They were raised to care for each other, which was also religious teaching. When the caregiver was a wife or a husband they referred to the Bible and stated they could not abandon their mentally ill partner because the Bible states that husband and wife should stay together in sickness and health. Rhonda mentioned: *I am not selfish, I think of my children and my husband first, they always come first ... you can say I am old fashioned, but that’s the way my parents raised me, and that is also God’s will ... I fear God.*

**4.3.2.2 Protecting in the hospital setting**

Families expressed dissatisfaction with the health care system. They complained that health care professionals did not provide adequate information about their mentally ill relative, did not involve them in the treatment plan, and did not provide support. The following was an example of how the health care professionals were presented.
The doctors were not helpful, they do not listen to you, and they do not want to, even when I ask them a question about my son’s behavior they answer me very briefly that I don’t understand what is going on. They make you feel uncomfortable when they seem to be busy. I feel that what he is doing is only to prescribe medication for my son and that’s it. I feel that he does not care or want to bother himself. He will only ask my son whether he is hearing voices or getting messages from the TV, I find it hard to communicate with the doctor. I need to know why my son is behaving like this? And what’s going on within him. I don’t know whether he is pretending or making it up? I don’t know what to believe.

Sam had a mixed opinion about the health care service and professionals. He had different experiences with the health care system. His first encounter left him angry and disappointed at the way he and his sister were treated. The second time, he was happy with the service, especially that the staff were very supportive in comparison to his previous experience. Sarah also described her frustration when she goes with her brother for an appointment with the treating psychiatrist: Each time I go with Samir for an appointment, I return home feeling distressed and depressed because of the way he (the psychiatrist) treats us. He makes us feel guilty all the time.

When asked about their satisfaction with the interpreting services, families responded with mixed opinions. At times they were satisfied and other times not. Some families reported that they had to correct what the interpreter was saying to the doctor, then the doctor would say: since you speak English, why did you ask for an interpreter? Families responded that: it was true that they could speak and understand English, but when the doctor uses difficult language, medical terms we do not understand, and sometimes the doctors just speak very quickly then it is hard for us to follow. Families mentioned that they rarely found an Egyptian interpreter. Most interpreters were either Lebanese or Syrian. Sometimes they found it hard to communicate with the interpreters because they used a different dialect from the Egyptian one. However, on other occasions, families reported being satisfied with the interpreting service, and were able to communicate effectively with them. Farah stated: This time, the interpreter was good and clear, I was able to understand her, she came on time, was
very pleasant, I even asked the doctor and her if she can always come to interpret for me each time I have an appointment with the doctor.

Protecting the person with mental illness took place at home and at hospital. Protecting at home was out of love, duty, love and duty, family traditions and religion. Families experienced mixed feelings when they were caring for their loved ones at the hospital. At times they were satisfied with the care their loved ones received, and how health care professionals treated them, at other times they were dissatisfied. The following section will reveal what the experience did to those who cared for and protected their loved ones.

4.3.3 What Has It Done To Me?

4.3.3.1 Being drained

All families involved in this study experienced feelings of being drained. Being drained was the result of the demands and responsibilities placed on their shoulders as well as the behaviours of the person with mental illness. This included physical work, physical health, physical, verbal and emotional abuse, the grief over the loss of their loved ones, feeling helpless, frustrated, confused, powerless, jealous of others, concerned and worried, embarrassed and stigmatized. Added to that were the financial difficulties, the sacrifice of their dreams, freedom and future, and the loss of their own identity.

Families complained of the amount of time and effort they spent with their mentally ill relative. They reported feeling physically exhausted, to the point that they doubted and questioned their own abilities in coping with all the demands and responsibilities placed on their shoulders in caring for the relative with mental illness. All this was in addition to caring for other members in the family, as well as the need to take care of themselves.

Peter, whose wife had major depression, had to look after her as well as his three young children, aged five, three, and a six months old infant, reported:

After my wife got ill, I had to do the shopping, cleaning the house, preparing meals, bathing the kids, preparing
formulas, and cleaning bottles for my six months' son ...
I could not cope with all the new responsibilities and the
kids ... I don't know for how long I will be able to
handle and cope with all this! I think if this situation
continues I will be physically and mentally drained ... I
am already exhausted. After being in this situation for
two years now, I do the same things everyday in a
routine manner. I feel like a machine working around
the house.

Similarly, Farah expressed how the behaviour of her son, who was diagnosed
with schizophrenia, was not only disturbing her, but also affecting her physical
health:

When I am sleeping, he comes to me and keeps talking
and talking until he wakes me up by all the noises he
makes ... I don't like this, I am an old woman, I have a
sleeping routine and my health is not the same as it used
to be when I was young. I need to sleep and rest, not for
myself, but for him, in order to be able to cope with
tomorrow's demands and work ... I do everything for
him, he does nothing, he leaves everything to me ...
smoking is also affecting my health, and my health is
getting weaker and weaker, I get wheezing in my chest
because of the smoke ... he smokes so heavily.

According to Rosa and Andrew, the experience was more than physical work. Both
had to endure the physical abuse silently and without complaining to anyone. Andrew
recalled one incident:

She punched me with a pen in my stomach...another
time, she went into the kitchen and grabbed a knife and
threatened me ... she throws cups, dishes and one time
she threw the video at me, but she just missed me, it
broke the wall ... one time I came from work and I found
the brand new mattress burned.

The physical pain that Rosa suffered had left her with bruises that she was unable to
hide from others. She had to face the world with those marks on her face:

When he starts shouting, we try to calm him down and if
you get in the way, you can get bashed, you get marks
on your face ... I did not enjoy the fact of going to uni
and my face is really red and swollen every day ... I would ring mum from uni to check that she was alright ... he would take advantage of her being a woman and alone and start hitting her ... when my sister arrives from school, first thing she would do when mum opens the door for her was to ask where is dad? She would remain quiet in her room, avoiding dad out of fear of being hit.

Besides the physical abuse, families endured the verbal and emotional abuse. Farah expressed how her son would call her names and insult her if she asked him to do something or clean something around the house. She elaborated: how hurtful it is to hear my son swearing at me and wishing me to die. Rhonda, the carer of her depressed husband reported: Many any times I feel like crying in front of my family, but I could not do this, I did not want them to know that I am sad or that my husband is hurting my feelings.

Andrew recalled:

one time I took my wife shopping, then she started to act in a bizarre way, she was stripping her clothes in front of everyone, when I asked her to put her clothes on, she slapped me on the face, I couldn’t hit her back. When I went home I was like a wreck, I kept crying until I fell asleep ... it was so humiliating and hurtful experience.

Rosa’s sufferings were overwhelming to the point of her admitting to a wish to die:

I’ve got uni, I have to handle the degree, the pressure of exams and stuff, plus home sickness, no friends, nothing, so all that and we get bruised at the end ... the atmosphere at home was so disruptive, noisy and he would use a language beyond the limits ... when it is time to return home from uni, you wish the day was still longer so that we do not have to return home ... what kind of life is that!! If I did not had mum by my side and the priest whom I confess to, I would have committed suicide a long time ago because it was too much.

Peter felt stressed out and emotionally drained: I feel that I am older than my age, I feel old and empty from inside, I just feel depressed.
Seeing their loved ones in a psychiatric institution was also a source of distress to families. Farah noted that each time she visited her son in the hospital, she felt depressed, and expressed her concern that she too might get depressed from seeing her son locked up in a mental institution. Another source of distress was the grief over the changes that had happened to their loved ones. Families compared the ill person before and after the illness and they felt that they were living with a stranger. Farah said:

He was so polite and loving, now he is very rude to me, now he treats me like his enemy and says “I hate you, I wish you were paralysed” ...This hurts me so much, seeing him like this. It is a big loss. I lost a wonderful son. I feel that my son is not my son ... he is a different person.

Similarly, Sarah’s hurt was due to seeing her brother deteriorating over the years, seeing him differently, seeing him as a stranger, a person who had changed completely from the person she knew in the past:

We were so close, we used to go to the movies together, laugh and joke with one another ... if I show you his photo in the past, you wouldn’t believe it is the same person he is now ... he was handsome and very elegant, now he doesn’t even want to shower.

Sarah’s hurt was very similar to the rest of the participants who had strong memories of their loved ones before the development of the mental illness.

Families felt frustrated because they could not do anything to change the condition of their loved ones, they did not know what to do to please them. No matter what families did to please them, they would not appreciate or understand. Families also felt frustrated because they did not know how to handle the behaviours of their mentally ill relative, how to deal with them when they were out of control. Rosa was frustrated because of her father who had paranoid schizophrenia:

You know when you spend hours and hours talking to him till 3 o’clock in the morning, trying to convince him what he is doing is wrong, whatever he is thinking is
wrong, that no one is against him ... he does not want to accept that he is unwell because if he doesn’t agree that he is unwell he wouldn’t take his medication, and when he doesn’t take his medication, he gets worse, and when he gets worse, he gets really more convinced that he is right ... it is just pointless talking and talking and at the end no change ... it is as if you are talking to yourself.

The families’ inability to understand and manage their mentally ill relative was a source of confusion. They did not understand the changes or the mood swings of their ill relative. At one moment, they would be quiet and pleasant, then the next moment they were the opposite. Families were not so sure of what to expect or not to expect, and how to manage them appropriately. Confusion and uncertainty were also experienced when families found it hard to manage their relatives at home. Some caregivers were uncertain whether they would be able to remain in the relationship. Some actually thought of leaving the relationship, but they could not do it. Some were confused; they did not know what they really want. Peter stated: Deep within me, I want to leave, but part of me keeps telling me to stay for the sake of the kids and the stability of the family ... I am confused, I do not know what to do? I cannot make a decision and be happy with it.

The inability of families to have control over their lives left them sad. They felt that they were forced to stay in the relationship, and to care for their mentally ill relative. Andrew caring for his bipolar wife, said: It is easier to live day by day and take it as it comes ... whichever this day brings with it, I will accept and deal with. Accepting to live in a certain way does not mean that you are happy with it ... do I have a choice?

Families reported that seeing other people having what they did not have, a stable happy life, was a source of envy to them. Peter revealed:

When I look at my friends, and compare my life to theirs, I feel jealous of them because they have a normal life, which I can’t have and they are able to fulfil their dreams ... I can’t help feeling jealousy and bitterness within me ... after all we are all human beings, and we have our weaknesses.
The concern and worry about the ill person was always there. Families worried and were concerned about the future of their ill relative, and about what would happen to him/her if the caregiver passed away. The concern was about who would look after the ill person when the caregiver was gone. Farah stated, *I am worried what will happen to him if I die, I am getting older and older, and he is very much dependent on me. Who will accept to look after him?*

Sam was also worried and concerned who would take care of his ill sister. *I know that when my parents are gone, I am the one who has to look after my sister ... I am not sure how I would handle this ... in the past, I was single, but now I am married and have my own family.* Concern was also reflected in a different way. Rhonda said that when her mentally ill husband got upset, he would leave the house even if it was late at night, without telling his wife where he was going. Farah stated that she was so scared about her son when he went out on his own, because people on the streets would not leave him alone. They would make fun of him, and many times he got beaten by strangers. She was afraid of losing her son:

*The hospital rang me to tell me that my son was found bleeding in the head... and someone stole his gold jewellery.... Each time he goes out for a walk on his own, I feel that one day the police will ring me and tell me that my son is dead. It is a scary feeling ... I feel very sad that my son has to suffer like that just because he is mentally ill ... how could people take advantage of him.*

Other feelings experienced by families which added to their distress were the embarrassment of the behaviour of the mentally ill person, especially if it was in front of a complete stranger or in public. Families noted that they were embarrassed by the way the ill person dressed in public. Farah mentioned:

*I feel embarrassed because people look at each one of us, and compare between the way I am dressed and taking care of myself, and the way my son looks... people will criticize us. I also feel embarrassed when a neighbor or someone comes to visit us, and he opens the door for them, wearing his underwear only, even in the winter ... I also feel embarrassed when someone visits, and find the house dirty. When we have someone*
visiting us, he wouldn’t come out from his room and greet them and this really embarrasses me.

For Sam, having a sister with schizophrenia and epilepsy was a source of embarrassment to him. *I feel embarrassed, when you are with your friends especially when you are a teenager. You get embarrassed very quickly. Ashamed sometimes ... you have to explain all the time what is going on.* With Sam, having to experience these embarrassments at an early age was hard for him. However, as he got older and more mature, he was faced with different problems affecting his relationship with his wife. Occasionally, he had to leave his wife at night to see his sister. As he stated, *the problems don’t end as you grow older, it is just of a different type.*

Sonia reported: *I would be sitting upstairs and I can hear him screaming downstairs, we had to run to every single window to shut them so that the neighbors do not complain.* On the other hand, Sonia confirmed that her embarrassment was only due to her father’s behaviors, not because he was mentally ill. She mentioned that she was not embarrassed to have a mentally ill father. *It does not bother me being at church and he can do whatever he can, I don’t feel ashamed, because I have got nothing to be ashamed of. I didn’t do anything wrong. But the person who really feels the stigma and embarrassment from people is Mum.* Rosa’s mother felt the stigma of being related to a mentally ill person. Rosa related the difference between her and her mother in the way they viewed mental illness and how they were handling the stigma to the age gap between the two of them:

*It depends on the perception of the human being to see it as a stigma or not. We didn’t see it as a stigma, but mum did, and when she goes to church, she feels upset about the way dad behaves and how people react to this ... I told her then they have no right to judge us.*

She described how society viewed her and her sister as being daughters of a mentally ill father: *When we go to church and dad is shouting, we hear people talking to one another and saying “these are the girls of the mad man” ... they say this in front of us, we can hear them saying this in our face.*
The stigma associated with mental illness prevented many families from seeking professional help. Andrew struggled to convince his wife to go to see a psychiatrist. He recalled:

*I had to spend hours and hours talking to her, telling her you will get better if you went to a doctor, he will give you medication and you will get better. Finally, she agreed, however, on the appointment day, she refused to go and said "I am not crazy, you want to make me believe that I am mad, I do not need to go to a doctor ... you want to make sure and have evidence that I am mad so that you can divorce me, no I'm not going anywhere."

Families also suffered financially as a result of having a relative with mental illness; this was especially true when the breadwinner was the person who had become mentally ill. When asked about how she managed to survive without any income at all after her husband lost his job and became depressed, Rhonda stated that they received support from some religious organisations such as St. Vincent de Paul, but that this help was not enough, the service was limited, and there were certain limits to the assistance they provided to people who were needy. *We had no money, and everyone was sending for us asking for money ... there were the bills, electricity, the rent of the house, etc. My family would help me sometimes, but not all the time.*

Rosa’s family also suffered financially because her mentally ill father used to take all their money and spend it on books and publishing papers with strange ideas. It was her mother who supported them financially. She talked about how they had to sacrifice things in order to survive financially. *All this mum had to endure on her own, she wouldn’t buy anything for herself so that she can pay for our expenses and to survive, and so that she can buy a book or a uniform for my sister.*

Similarly, Andrew complained of the way his wife was handling money:

*She would spend all the money on clothes or dining out at expensive restaurants. She would give half of the shopping to her friends without charging them ... I felt that they are taking advantage of her financially ... I had $90,000 in the bank, she wasted it all, she even made me sell the house, now we are renting ... she kept whingeing about my job, until I resigned.*
4.3.3.2 Sacrificing my own dreams, freedom and future

Families had to make sacrifices whether willingly or unwillingly for the sake of their ill relative. These sacrifices took the form of giving up their own dreams, freedom and future. For example, Sarah felt she was a victim of circumstances that she had to give up her education due to lack of support from her family. It was not a sacrifice that she willingly accepted, nor something that she wanted to do, but there were obstacles beyond her control which prevented her from fulfilling her wishes and desires. This, in turn, caused her great distress and to feel resentment towards her parents and particularly her mentally ill brother, whom she described as her main obstacle:

_It was Samir (her mentally ill brother), whom dad was very interested to give the best education rather than the rest of us, though he (Samir) was not really interested in education.... But for me, I was sure of what I wanted to do exactly, I wanted to finish uni and find a job.... I asked mum to look after my kids until I return from uni, she refused and told me “she can’t leave Samir alone at home” ... Samir was standing in everyone’s way ... I feel I am left out and that I was at the end of the list of my parents’ priority ... Samir was on the top of their priority._

Similarly, Rosa stated that prior to migrating to Australia:

_We thought, he (her father) was distressed because the rest of his family were living in Australia, so we said OK, let’s move to Australia, may be he will feel better being close to his family ... it was not fair, because mum had no one in Australia, mum had a very good job in Egypt, my sister was in private school and I was a medical student in my final year when I was dragged into this ... all my friends now have their own private practices and I had to start all over again, I have just started dentistry ... we all sacrificed because of him I felt victimized and dragged to do this ... I had no choice except to give in._

Families experienced a loss of their dreams, and their attitudes towards the future changed. After the onset of the illness, the majority of families recalled losing motivation and interest in their lives and in the future. They were present oriented.
Peter, who had cared for his depressed wife for four years, expressed this loss as follows:

All our dreams are shattered ... Now I have stopped studying. What for? I do not have the energy or the mood to do anything ... I lost all my motivation. I know I will never be able to achieve anything I wished and planned for ... I do not bother to remember what happened to me yesterday, I do not think or want to remember the past, I am living moment by moment as it comes. I do not care much about the past, the present or the future, this is because every day seems the same, like any other day ... there is nothing special about any day and they are all the same ... I can not change my present and also I can not change my future, so why think about it? What will happen will happen. What is meant to be will be, regardless, whether this thing is what I want or not.

Families complained of having to give up certain life pleasures in order to please the mentally ill person. They described their lives as being “restrictive”, and the experience as limiting their freedom. Andrew’s life was disrupted to the point that he hated going out shopping with his wife and he describes the restriction his wife put on him as follows:

it is as if I can’t breathe anymore. If someone – a woman looked at me in the street, she gets very jealous. She accuses me of looking at other women, which I do not do. I even, to avoid any problems, I try not to look at anyone, which is an unusual and abnormal thing to do. It is very hard not to look accidently at other people.

Caring for a person with mental illness had a devastating effect on families. The caregivers, by taking the responsibility of looking after their loved ones, had to make sacrifices in all ways: financially, socially, physically, and emotionally. In their attempt to please their mentally ill relative and to meet his/her needs, families had to give up a life that they were used to, and accept the changes. However, for most caregivers and their families, accepting the change was hard. Even when they admitted that after living with the mentally ill for many years, they were more accepting of the situation, they were not happy about it.

Chapter 4 – The Experience
4.3.3.3 Losing my identity/role

Within the Egyptian culture, there are role expectations for both the man and the woman. Rhonda had to deal with societal and role expectations when her husband became mentally ill.

When the man gets ill, he loses his self-esteem, his trust in his wife, he thinks that because he is mentally ill that his wife will leave him or disrespect him. Then he will start fighting and arguing with everyone around him, a way to prove to himself that he is a male (masculine).

Similarly, when the woman was mentally ill, and the husband was the caregiver, he felt overwhelmed with all the responsibilities and duties placed on his shoulders. Andrew stated:

Instead of my wife who should be looking after the family, now I am the one who has to take care of everyone, with no one to take care of me.... As a man there are certain duties in the house that are typical for women not men to do. Now I am doing everything.

Loss of one’s identity was also related to unemployment or loss of one’s job. Peter elaborated that he could not have a job, because he had to stay at home to look after his ill wife and children. He expressed how he felt about receiving money from the social security:

We are receiving social security benefits, which I do not feel happy and proud about, but I had to accept it. My situation forces me to accept this money from the government because I do not have any other income to support my family ... I feel like a failure because I do not have a job ... I do not want to be a burden on the government ... I feel that the money I am receiving from the government is like someone is giving me a donation out of sympathy, not because I deserve it and worked hard to earn it ... When me and my wife came to Australia, we wanted to work, find a job to support our children ... I never wished to be living on the dole and taking money from the government. Having to accept this money reminds me of my failure as a man, failing to provide for his family as a breadwinner. It affected my manhood ... it is expected that the man works and gets money and should be able to provide for his family ...
Sonia also reported how her mother had to work in order to provide for them, instead of her father who was mentally ill.

4.3.4 What Has It Done To Us?

Having a relative with mental illness did not only affect the caregivers, but also the rest of the family. Families were living in isolation for two main reasons. One was that society would not accept them, the second was that families tended to isolate themselves from others because of the embarrassment caused by the behaviours of their loved ones. This alienation left the families feeling alone and lonely. The experience also caused a change in relationships between family members and friends. At times, it disrupted the husband-wife relationship, or caused disruption between siblings, and at other times, it caused disruption between healthy siblings and parents.

4.3.4.1 Living in Isolation

Being alone and feeling lonely were among the hardest experiences reported by the caregivers. They were afraid of being alone, having no one to talk to, and little support. They felt that even their friends were not interested in listening to complaints or sad stories. They added that everyone was busy with their lives, and there was no time to listen to other people’s complaints, so they ended up being alone. Even when there were people around the caregivers, they reported that they still felt lonely, because no one cared to listen to their needs and how they felt. Andrew explained: *I am doing my best to meet everyone’s needs, what about my own needs? Who cares to find out and help me to deal with my grief and loss? No one!* Similarly, Peter, Sam and Rhonda felt lonely and neglected. Peter elaborated:

*I am still young and I need a woman in my life, a woman that understands and shares my feelings. I need a person that can support me, a person I can talk and listen to…. My wife is present with me physically only, but she is very much distanced from me. She is near me, but at the same time far from me.*
Due to the behaviour of the person with mental illness, the caregivers found it hard to invite people home because they did not want to upset the mentally ill and they wanted to avoid any embarrassment resulting from his/her behaviour, thus having to live in isolation. On the other hand, it was hard to convince their relative with mental illness to go out and meet other people. They felt that everyone knew that their relative was mentally ill, and would treat them badly, or make fun of them. They preferred to hide from people. The caregivers felt that people did not want to see or relate to a family who had a person with mental illness. Farah stated:

_All people know that my son is mentally ill, they make us feel guilty about his condition, as if we are the ones who caused him to be ill. People look at us in a bad way. But what can we do, we can’t change anything, it is his fate that this happened to him and to us. People do not like visiting anyone who is mentally ill, but what is my fault in all this, what is my fault for not having people visiting me because of my son’s mental state. I feel lonely staying alone with no friends to say hello._

This statement reflected societal attitudes towards the mentally ill and families of the mentally ill. It reflected social injustice.

Rhonda, who was looking after her mentally ill husband, expressed similar feelings as a result of her husband’s behaviour:

_My family stopped visiting me at home because of his behaviour. He would shout and yell at me and at the children, he embarrasses me in front of my family, and friends. He would not differentiate or care whether there are visitors at home or not. This left us feeling alone and lonely, without any one to support us._

In spite of recognizing and facing the difficulties in caring for their relatives, the caregivers continued to care for them, and feared the loss of the company of the person, and being alone at home. Farah explained how she continued having her son at home rather than sending him to a psychiatric hospital because of fear of being alone:
A long time ago, I sent my son to the hospital because he was hard to manage, and I felt relieved for a while, but this happened when my husband was still alive, but now I am alone and he (her son) is the only person in my life, he is the only person who I spend most if not all my time with... I can't let him go, it is very hard to be alone... I am scared that if the police came to take him to the hospital, everyone will know that I am staying alone at home, and anyone can come in and kill me... also I think of the neighbors what will they think of me, they will think that I am a cruel mother to let the police take my son.

4.3.4.2 Change in the relationship with family and friends

All participants stated that it was the behaviours and attitudes of their loved ones which were destroying the peace and stability of the family. Sarah felt she was being victimized: It was not fair that one person (her mentally ill brother) kills/destroys the rest of the family... even my older brother agrees with me on that.

Rhonda mentioned that her husband's depression was affecting her and the children as well. She described how her husband would stay alone in his room, isolating himself from his family. He would not allow the children to come near him or talk to him, and he became angry if he heard a child crying. This behaviour was distressing to her and the children. When he (her husband) behaves like this, I become distressed and I feel that I have no energy anymore for the kids and for him too. Sometimes when my husband upsets me, I put it on the kids, I know it is not fair.

Sarah's relationship with her ex-husband and her father-in-law was affected by the stigma associated with mental illness:

It should not affect your relationship with others, but it did... He (her husband) always patronizes me and tells me that "your brother is mentally ill"... when we have a disagreement like any couple, the first thing he hits me with, he would say "yeah, you are crazy like your brother"... he does not say you are ill, but you are mad like your brother. When you hear this for the first time, you feel disgusted and you tell yourself, this is rude manners, second time you hear it, you start thinking about this word, you do not believe that you are mad, but it hurts and you start having doubts about yourself.
... could it be true what he said about me, could it be true that I am mad like my brother!! So it starts to affect you psychologically, it shakes your self-confidence... even my elder son, when he gets angry about something, he would tell me “it is in the genes mum”. One time I had an argument with my father-in-law... he told me that my family is a crazy family and that the whole family is mad, not just my brother.

Samir’s mental illness was disrupting the mother-daughter (Farah-Sarah) relationship and was a source of distress to both of them:

I got very angry with mum when I knew that she allowed him (Samir) to stay with her at home, after spending two months in rehabilitation and he was just starting to get better, he had to stay for six months in rehab... I told her your love for him has destroyed him... you are not helping him... he should remain in rehab... he knows that mum loves him and he manipulates her to stay with her at home and when I tell that, she gets upset with me... she does not visit me because of him... one day, I told mum that she loves Samir more than me, and that she doesn’t care much for me and I meant nothing to her... I would tell mum “he is your son and I am your daughter, and I need you so do my kids... the kids need their grandmother”.

Families complained of the desire of the mentally ill person to possess and control the caregivers. They wanted the caregivers to give them full attention, love and care without sharing that love with anyone else, for example, the rest of the family or a friend. Sam stated that his sister always disrupted his relationship with his wife:

She gets jealous about seeing me with my wife. When we go for a visit, she insults my wife and one time she wanted to hit her, so we have to make the visit short and we return home fighting over what happened. Then the next day, I would talk to my sister and my parents who always support her, saying it is not her fault, she doesn’t know what she is doing, so I get angry with my parents and my sister and decided to limit my visits to them and keep my wife away from my sister.

Farah was torn between her son who had schizophrenia and her other children and her grandchildren:
This is not fair, I still have my other children and grandchildren whom I also love and care about. I can't distance myself from them because of my ill son ... I always tell him that I love him, but he wants me all for himself. I don't know what to do? I can't prevent my other children and grandchildren from coming and visiting me, I also need them, I need their company, they are the only ones who come and visit and say hello to me.

The possessive behaviour of the mentally ill relative did not stop at that point. The caregivers complained of the way their relative interfered with their relationships with other people. The caregivers reported that their relative would turn the neighbours or friends against the caregivers in an attempt to disrupt or end the caregivers’ relationships with other people. That behaviour distressed the caregivers and they ended up with no friends, and feeling lonely. Rhonda told of how her husband got angry when he found her talking to her family or a friend over the phone. He had suspicious ideas that people would turn her against him.

Caring for a mentally ill relative did not only affect the direct caregivers, but also other members of the family. The behaviour of the mentally ill was a source of distress to other family members. Peter described this distress:

I feel scared that the current situation with my wife who is depressed will affect my kids too ... I do not want the kids to live in a sad, tense environment...they see their mother constantly crying and they ask me "why is mum crying and sad?" ... They are still young to understand and handle what is going on with their mother ... I am afraid they may not cope with this.

4.3.5 How Do I Survive?

Families strived to survive with all the difficulties in their lives, with all the responsibilities and multiple roles. The participants managed to survive and cope with their experiences. They shared a common strength which kept them going despite the hardship of their situation and lack of support. Families used different coping strategies, some of which worked well for them at certain times and not at other times, and sometimes certain ways of coping worked better than others. It was a
matter of trial and error. They tried different things and they learned to cope the best way possible. Coping took various forms. Families hoped for a miracle and had faith in God, they remembered the good times they had spent with their loved ones before the illness, accepted reality, compared their lives to others and sought professional help.

4.3.5.1 Living in hope
Families lived in hope for a better life for their loved ones. Andrew hoped for a miracle to happen to his ill wife:

*If God really loves me, He can change my miserable life...How will he do this? I don't know! But I hope for a miracle to happen and to bring me back my wife healthy and happy as she used to be. Only when this happens I will go back to God... I will not shut Him out of my life entirely, I will wait for God to show me his love, who knows may be a miracle will happen.... No one can help me in this...only God can help me ... the only thing I can do is to hope that God will intervene and do a miracle.*

Similarly, Farah stated:

*I still have hope and faith in God, that He will cure my son, but I do not believe in medication and medicine that they will help my son, unless God makes it happen, that one day when I wake up in the morning and find my son a new man, like he was in the past.*

Some caregivers believed that seeking God's help, going to church, and their religious beliefs helped them in coping with the caregiving experience, and helped them to be more accepting of the person with mental illness. Sarah mentioned *going to church is the best thing I do when I feel stressed out ... I feel calmer and relaxed after I go to church ... returning to God has given me strengths to cope with my situation.* Rosa, though deeply distressed by her father's behaviour while he was still living with them under the same roof, stated that it was only her mum and going to church that helped her to cope with the stress, otherwise she could have committed suicide. *Going to church was the only refuge for us ... the time that we went to church was the only time*
we have some peace and rest. Her faith in God gave her strength. She believed that
God was fair to people.

4.3.5.2 Remembering good times
The majority of the participants described their relationships with their mentally ill
person as being good before the illness. Remembering the good times, their
relationship, the happy memories families shared with their loved ones in the past
helped them to endure the experience of the mental illness. Remembering the good
times was also one of the factors that helped family members to stay in the
relationship and not to abandon their mentally ill relative. Peter stated:

I can not leave her because of the good times we shared
together in the past...we shared more than ten happy
years together, she was the best wife a man could ever
wish for, she was full of energy and happiness. When I
look back at those years, and what a good wife and
mother she was, I tell myself “it is not fair to get rid of
her now, who will take care of her? She has no one
except me”...I keep telling myself, what if the reverse
had happened, and I was the one who became ill? I
know she would have never abandoned me. So why
should I do this to her?

Rhonda shared a very strong bond with her ill husband; they were deeply in love with
each other, and she had had to change her religion to marry him which was a very big
issue and unacceptable within the Egyptian culture. She had married him against her
family’s approval, which was also culturally inappropriate. She stood by him, and
married him despite all the difficulties she had to face. Consequently, she would not
let him go and continued to hope for a happy life with her husband. They had shared
wonderful years together before the illness, and she believed that her family would
survive, and she looked to the future. Interestingly, some of the caregivers also
admitted that despite all the negative effects of the experience on them, they felt that
after those many years caring for their mentally ill relative, they had gained some sort
of experience/expertise as well as strength in dealing with their mentally ill person.
They were more accepting of his/her behaviour, although they were not happy about it
all the time.
4.3.5.3 Enduring and accepting the realities

The participants learned to endure their situation over time. In their ‘everydayness’ experiences, they learned to accept the situation projected at them and accepting it was a way of surviving. Sam felt that looking after his ill sister while his parents were at work was restricting his social life: *When mum and dad are at home, I make sure I go out and have a good time and escape, you have to get out of the house, everybody needs to escape, you have to go away, you have to go out for a night with your friends, anything like that, but you have to escape.*

Families managed to survive by accepting their situation, by accepting that this was their fate and they had no control over it. They reflected that no one could change his/her fate. It was something that was meant to be whether they liked it or not. When I asked Sam about how he was coping over time, he replied:

*You learn to live with it, I think this is the main thing, you actually learn to live with it, you learn to cope and you realize that you have to cope, and it works out ok ...You go through stages where the first months you are very shocked and then you are concerned and then you start going through stages where you are embarrassed and then you go to other stages where you just learn to deal with it and be more accepting, you learn how to cope as you go...about after a year you start coping again ...you have to adjust to it ... it never gets easier, you just learn to cope better. That’s the best thing about it, it doesn’t get easier, you just learn to cope better ... like everything has been the same for the last ten years, nothing has changed, but we just learned to cope with it better so it actually seems easier but it never is/gets easier.*

Another way which helped families to survive and accept their situation was by comparing their lives with other people who were in worse situations. That helped them to be more accepting of their situation, after recognizing that their experience could be nothing when compared to other people’s experiences. For example, Peter noted:

*I tell myself, and my wife too, at least this happened to one of us (parents) instead of to one of our children ... at least our children are safe and healthy. I compare my*
situation to other people who are in a worse situation, I feel that what I am going through is much better than other people. I have seen children in wheelchairs, or suffering from mental illness, I feel that being in this situation is better than seeing one of my kids physically or mentally ill.

4.3.5.4 Seeking professional help

Only one participant stated that she sought professional help to cope with the stress of caregiving. Rhonda mentioned that she was seeing a counselor but not however, on a regular basis. She had to see her counselor without telling her ill husband, because he would not allow her to see one. She related:

I felt better after seeing a counsellor. The counsellor gave me relaxation tapes and taught me how to relax when I feel stressed out or angry ... at the beginning I enjoyed these sessions with the counsellor, but not for long ... now I feel bored with it, I can't stand listening to those tapes all the time. I like action, so I go for walk or exercise at home.

The above section has reviewed the strategies families used to survive with the caregiving experience. The majority of families hoped for a miracle and the experience brought them closer to God and they gained strengths to survive. The good memories families shared with their loved ones in the past helped them to continue caring and protecting their loved ones, in spite of everything. Those good days were something that families held on to in order to survive. Families became more accepting of the realities of their situation and learned to endure and survive by comparing their situations to those of others. One sought professional assistance, which helped temporarily, but again she learned to manage on her own, without any help or support from others. That was the main strength in their experience of having a relative with mental illness, that, in spite of everything, they survived. It was a survival experience.

4.4 Summary

This chapter introduced the participants and the findings, which provided an insight into one way of being-in-the-world, being the families of people with mental illness. The above quotes brought to light the meaning families gave to their everyday
experiences, and gave answers to: Why did this happen? How do I protect my loved ones? What has it done to ME? What has it done to US? How do I survive? Families were shocked by the diagnosis and the changes associated with it in their loved ones. They blamed God, themselves, the person with mental illness, parents, medication, the evil eye, magic and evil spirit possession. Families’ protection to their loved ones at home was due to love, duty, love and duty, Christian beliefs and family traditions and upbringing. At the hospital, families’ protection of their loved ones was reflected in their experience with the health care services and health care professionals. Protecting and caring for a relative with mental illness not only affected the individual family member, but also the rest of the family. The experience affected them physically, emotionally, socially and financially. Families had to make sacrifices, give up on their own dreams, freedom and future and they lost their own identity. The experience disrupted the unity of the family and the relationships with friends. However, in spite of everything, the families survived.
CHAPTER 5

DISCUSSION
5.1 INTRODUCTION
This study has provided an insight into Egyptian people, living in Australia and caring for a relative with mental illness. This chapter ties the study’s findings to the initial research question and relates the findings to the existing body of literature. Findings of the study revealed that there were similarities and differences between the Egyptian caregiving experience and the caregiving experience reported in the literature. This chapter discusses these similarities and differences in the light of the existing literature on caregiving. The major similarities were in the ways families cared for their loved ones and their experience of burden of care. The differences were in the way Egyptian families viewed and dealt with mental illness. The following issues were found to be accentuated among Egyptians: the role religion played in the way families viewed and coped with mental illness, families’ experience with stigma and its effects on them, the role of immigration in families’ experience of isolation, and the impact of immigration on intergenerational differences. Implications of the study findings for practice will be discussed at the end of this chapter.

5.2 BEING DRAINED AND OVERWHELMED
The participants of this study revealed the experience of caring for a relative with mental illness to be one that was overwhelming and draining. The majority of participants experienced stress related to their difficulties in managing the person with mental illness, the unpredictable and embarrassing behaviours, and the demands and extra responsibilities placed on their shoulders in caring for their loved ones, besides caring for other dependent family members. This is congruent with the literature on caregiving (Doornbos, 1996; Lefley, 1987a; Rose, 1997).

All participants in this study continued to care for the person with mental illness despite the many difficulties they experienced. The caregiving role did not stop even when a sibling who was once the primary caregiver married and lived in a different house. Siblings of people with mental illness continued to care for their loved ones in time of need or an emergency. The family would gather again to provide support to each other. The experience left them physically, psychologically and financially drained. This finding is consistent with a large body of research on the effects on carers of a person with mental illness. Previous research showed that families suffered continuing strain and that their stress level increased over time (Maurin &
Boyd, 1990; Noh & Turner, 1987; Reinhard, 1994b). This was particularly true in this study where the carer was an elderly parent. Though carers learned to cope better, the experience never got easier. The older the parent caring for a son/daughter with mental illness, the harder it was, due to diminished energy and overall physical health, and the psychological and emotional drain they had endured throughout the years of caring.

The majority of participants in this study were at a high risk of developing mental health problems, which was expressed explicitly by a number of participants who either felt depressed, anxious or who were suicidal. This finding was consistent with other studies, which found that caregivers of relatives with mental illness showed signs of physical, emotional and mental distress (Gibbons et al., 1984; Natale, & Barron, 1994; Winfield & Harvey, 1993).

5.3 WAYS OF CARING

All participants felt they had no choice except to make sacrifices and to give up their own needs for the sake of their loved ones. They did so because of their unconditional love, and because of duty and obligation to maintain family ties and to keep the family together. It was due to religion and family tradition that they continued to look after their ill persons and not abandon them. When providing care was out of love rather than duty or obligation, participants were more willing and ready to protect and care for their loved ones no matter what, even if they had to give up all the pleasures in life. Love bonded participants with the person with mental illness and helped participants to be more dedicated to the ill person, and to cope better as the illness progressed. The good times and memories families shared with the person with mental illness before he/she got ill, helped families to provide love and care for their loved ones. This finding was supported by Neufeld and Harrison (1998), and Kellett (1999) who found that the quality of relationship before the illness influenced the present interaction with carers and the ill person. On the other hand, when care was out of duty, participants felt trapped and viewed their caring role as something that was forced on them.

The way participants experienced and viewed their caregiving role was influenced by the familial relationship they had with the person with mental illness. Parents'
protection of, and care for, their ill child differed from that of the siblings of the ill person. Mothers who had a mentally ill offspring were against the idea of hospitalisation. This could be due to a stronger mother-son or mother-daughter bond than that among siblings or it could be due to the differing view of treatment across generations. It was harder for parents, especially mothers, to let go of their loved ones. It was a way of protecting their loved ones. Another factor could be due to the fact that although mothers knew that their son/daughter suffered from a mental illness, putting them in a mental institution was just reinforcing this fact, which was a highly stigmatized issue among Egyptians. Noh and Turner (1987) revealed similar findings, where differences existed between parents, siblings and spouses in their reactions to the caregiving role.

5.4 EXPERIENCE WITH THE HEALTH CARE SYSTEM

Participants in this study expressed a mix of feelings and attitudes towards health care professionals. At times, they were satisfied when the staff provided emotional support, were patient and provided families with information on their loved ones’ condition. At other times, participants were dissatisfied and frustrated with health care professionals for being inconsiderate, for blaming and accusing the family, not involving them in the care of their loved ones, not giving them adequate information and being culturally insensitive. This finding is congruent with the literature (Doornbos, 1997; Eakes, 1995; Gorman, 1997; Lefley, 1987a; Rose, 1997; Song, Beigel & Milligan, 1997; Tuck, et al., 1997). This finding emphasises the need to provide families with adequate information, provide support and be more sensitive to the needs of families, including the cultural needs of clients and families who come from diverse cultural and linguistic backgrounds. This includes the use of appropriate interpreters, providing written information in the language spoken by clients and their families and understanding their cultural background.

As expressed by the participants in this study, the type of support needed from health care professionals includes gaining information on the nature of mental illness, its prognosis, management of the person with mental illness and the support services available to them in the community. A vast body of literature supports the importance of providing families with adequate information and role of social support in assisting
families to cope with the caregiving role no matter what culture they come from (Bartol, Moon & Linton, 1994; Reinhard, 1997; Winfield & Harvey, 1993).

5.5 WAYS OF SURVIVAL
The majority of participants felt they had no choice except to care for the person with mental illness, as they had no one else to care for them. Participants recognised that the person with mental illness was totally dependent on them, which gave the participants a sense of belonging and achievement. Though daunting, it gave them a reason to survive, knowing that they had to look after their loved ones. Another factor that was common among all carers except one, which helped them in coping, was remembering good times. The participants’ past influenced their present and the future possible ways of caring and coping with the caregiving role. The good memories participants shared with their loved ones before the illness helped in coping at times of distress with the exception of one particular participant who had no good memories to recall of her father who had mental illness. To her, her father had always been the same before and after the illness, so the illness did not make a difference to her. However, for the majority of participants, the quality of the relationship with their loved ones in the past influenced their relationship with the person with mental illness in a positive way. This was consistent with Heidegger’s (1962) perception of time in terms of the past, present and future, which he viewed as three interrelated aspects of a person’s existence, in that they influence each other. It was through the past and the present that people were able to see possibilities for their existence by projecting to the future and seeing possibilities in the future.

In this study, participants’ experience of burden was never-ending and in spite of the fact that they complained of the increased demands and stress resulting from the many years of caring for their loved ones, they managed to cope better over time compared to their early years of providing care. This could be attributed to the participants’ learned endurance over time. They gained some understanding of patterns of behaviours exhibited by their loved ones and learned through trial and error how to manage the loved ones. It was as if they gained mastery over the situation and learned what to expect of their loved ones. They had passed the stage of shock. They were faced with the realities, which they could not escape or deny. Noh and Turner (1987) found a relationship between carers’ sense of mastery and level of stress. As
carers’ confidence and ability to manage both expected and unexpected circumstances increased, their level of stress decreased.

According to the participants, the stress level did not get better, they just learned to cope better over time. A second explanation for participants’ coping better over time could be that the participants became more accepting of the diagnosis and came to terms with reality. At the beginning, participants were shocked. They denied, disbelieved that their loved ones were mentally ill and they had uncertainties about the illness and medications. In the initial stage, they resisted the idea strongly and could not believe that this was happening to them. Some participants did not believe that depression was a mental illness. It was only when time went by, and the symptoms got worse that participants became more aware of the seriousness of the illness. Knowing that they tried everything to help their loved ones and things did not change, they became more accepting of the diagnosis, which helped them in coping over time. They became aware of the symptoms and how to manage on their own. The practical skills they developed were not a result of professional support and education, rather the skills gained over the years caring for their loved ones. This finding was similar to Miller et al. (1990) study, where they found that families experienced low level of initial grief, but higher levels of present grief and distress. Families in their study were not fully aware of their losses at the initial stage due to confusion, disbelief and hope for cure. It was only later in time that families were able to deal with their losses and fully understand their role as caregivers and the effects this had on them as carers and on the family as a whole.

Striving to survive was a pattern that was found among all participants. The findings of this study have indicated the important role spirituality played in the survival of the participants. The majority of participants identified that having faith and turning to God was the primary source of strength helping them throughout their journey of caregiving. Going to church and seeking help and religious guidance gave participants the ability to survive in spite of everything. Being close to God gave the participants hope for the future, which gave them emotional strengths. The positive role of spirituality in coping was consistent with previous studies across cultures. However, it should be noted that in this study, spirituality was the major way families managed to cope with their caregiving role as compared to other studies, where
families used a combination of coping strategies (Badger, 1996; Doornbos, 1996; Rose, 1997; Tuck et al., 1997).

The above section revealed that Egyptian caregivers had much in common and shared similar experiences to those of Western and other cultures. The following section aims at shedding some light on experiences that were accentuated among Egyptian caregivers living in Australia as compared to those identified in the literature. Those experiences evolved around four issues: tradition and religion, stigma, immigration and isolation, and immigration and intergenerational differences.

5.6 TRADITION AND RELIGION

Tradition and religion influenced the way the families viewed mental illness and the responsibility of family for the care of mentally ill relatives. As mentioned earlier, in Egypt, carers would rely mostly on their extended families for support. Traditionally it was expected that any family member would provide care for the person with mental illness. At all times, there would be somebody willing and available to offer and provide support and care to the person with mental illness and his/her direct family. The support could be financial, physical, social and emotional. Findings of this study revealed that some participants were against hospitalisation of their loved ones. Previous studies have showed that of the psychiatric patients who had been discharged from hospitals into the community, only 25% were living with their families where the majority were ‘whites’ (Jones, 1996). Similarly, Doornbos (1996) found that 61% of people with mental illness had various living arrangements outside the family home, whereas 39% resided in the family home. Other studies showed that more than 50% of mentally ill migrant people lived with their families (Herrick & Brown, 1998; Lantican, 1997). When the caregiver was an elderly parent, it was a social and family expectation that the siblings of a person with mental illness would provide care for their ill brother or sister, when the parent became older or passed away. This tradition ensures that the persons with mental illness will always have someone to care for them. As it is a cultural and family tradition and expectation for siblings to share the caregiving role, all siblings in this study reported that it would be their role to be caregivers when needed. However, in Greenberg, Seltzer, Orsmund and Krauss’ study (1999), only one-third of siblings of people with mental illness were expected to assume the responsibility of caregiving for their loved ones in the
future as compared to 60% of siblings of adults with mental retardation. This implies that there are cultural differences in the level of family tolerance of mental illness, especially among siblings with their cultural and family expectation of continuing caregiving for their loved ones. Findings of this study showed that Egyptian families were against the idea of having their loved ones living in other accommodation or away from the family as they considered it as abandoning them. As a result, Egyptian families showed very high tolerance of the behaviours of the person with mental illness and the demands and sacrifices associated with caring, including siblings' caregiving commitment.

The role of religion played an important role in the way families viewed and coped with mental illness. Relatives in this study were from Christian backgrounds, except for one relative who was Christian but had converted to Islam. Some relatives attributed mental illness to the evil eye, use of magic and evil spirit possession. They supported this view by referring to the Bible and its discussion of evil eye, magic and evil spirit possession. For example, families referred to the Bible where possessed people were thought of and treated by others as mad, but were healed by the hands of Jesus who expelled the evil spirits from their bodies.

Relatives expressed that for religious reasons they could not abandon their loved ones, especially when the carer was a husband or wife. They referred to having taken an oath in front of God and people to continue to love and care for their partners in sickness and in health. Not a single relative mentioned going to a support group or being involved in community groups apart from going to church. Church was the main buffer for many families caring for a relative with mental illness.

5.7 Service Utilisation

Findings of this study revealed that there was a delay in accessing and utilising the mental health services. This was mainly related to families’ high tolerance of the symptoms of mental illness, reluctance to use the mental health service for fear of stigma and the beliefs and attitudes held about mental illness. Relatives related mental illness to evil spirit possession, evil eye and magic and this prevented them seeking professional help at an early stage. Some relatives used religious leaders to help cure their loved ones as their belief was that mental illness was due to spirit possession,
which needed exorcism. The belief that mental illness is related to the evil eye, magic use and evil spirit possession is different from the way Western cultures view mental illness. Furthermore, families initially did not believe that their loved ones were mentally ill, and thus did not need medical treatment. It was only when the symptoms were severe that they started to accept them as indicative of an illness. This was especially true when the person with mental illness was diagnosed with depression or other affective disorders. Three carers were looking after partners who either had depression or bipolar disorder. They reported that they believed that their loved ones were going through a tough time, which would resolve spontaneously and that it was something that any person could go through as a result of life stressors. For example, some carers attributed the symptoms and/or bizarre behaviours exhibited by their loved ones as a reaction to stresses such as those associated with immigration, leaving the extended family in the country of origin, loss of friends due to immigration or loss of job and status. They referred to mental illness as ‘stress’ rather than an illness. It was only when things did not get any better that they started to realize that their loved ones needed professional help.

Relatives stated that they did not know what services were available to them in the community that could provide support or help to them and that no one had informed them about these services. In Australia, carers may belong to a support group, seek professional help and use other strategies to help them cope with the caregiving experience. This in turn opens the door for families to gain support, meet people, share their experiences with others and gain education and information about mental illness. In addition they can learn how to manage the person with mental illness and learn more about the other services available to them. On the other hand, in Egyptian families, because of the stigma, language barrier and lack of services that are linguistically and culturally appropriate, families miss out on the opportunity of socialising and gaining access to support services in the community. Consequently, there is a need for making culturally and linguistically appropriate services available to immigrant families. However, this would not guarantee that Egyptian families would access and utilise these services, such as going to a support group, because of cultural reasons such as the stigma, shame and embarrassment.
Carers also raised the issue of the inappropriateness of the interpreting service. Carers reported that at times they were not even asked if they needed an interpreter; at other times, they expressed their dissatisfaction with the interpreting service because the interpreter used a different dialect from the Egyptian one, which was sometimes confusing. Caring for a relative with mental illness can be distressing and overwhelming even when carers have the linguistic skills to talk to health care professionals and get the needed information. Being a migrant with English as a second language exacerbated the distress and anxiety level for carers, due to their inability to communicate with health care professionals. The language barrier added an extra stressor on Egyptian carers’ lives compared to English speaking carers.

5.8 STIGMA

The stigma associated with mental illness is one of the adverse effects families in all cultures experience. The effects of mental illness and the stigma on all the participants was marked and pervaded all of the themes related to their experience. Mental illness is highly stigmatised among Egyptians, and is associated with shame, guilt and bad reputation (Meiser & Gurr, 1996). The stigma and shame created a significant barrier to families asking for or receiving help from mental health services and other sources. This in turn left participants with a great burden in having to deal with their caregiving role on their own. Findings of this study and those identified in the literature showed that there are cultural difference in families’ experience and perception of stigma. For example, Read and Harre (2001) found cultural difference between Maori and European participants and Asian participants in their perception and experience of stigma, with Asian participants experiencing higher levels of stigma and prejudice.

The sense of stigma had devastating effects on the whole family, and disrupted many relationships which were once strong. Stigma caused family members to blame each other, the person with mental illness and societal attitudes for the destruction of relationships. Stigma was highly related to and contributed to families being isolated, alone and lonely. Although stigma and the effects of caring for a person with mental illness affected families socially as demonstrated in the literature, Egyptian caregivers and their families experienced these effects in a different way from Australian families. Wahl and Harman (1989) found in their study of Western caregivers’
experience of stigma that most families believed that stigma was associated with mental illness, but only 56% actually felt they were directly affected by the stigma. Another study by Doornbos (1997) revealed that only 10% of 108 white female caregivers who participated found stigma to be an issue. Participants in Doornbos' study reported a perception that the general public was uninformed about mental illness. Due to the fact that mental illness is highly stigmatised among Egyptians, some participants kept it secret from other family members. Some participants tried to hide from others that there was mental illness in the family and this led families to be more isolated and to limit their social contacts for fear that people would know about the illness.

5.9 IMMIGRATION AND ISOLATION

The experience of caring for a relative with mental illness affected families socially. This finding was reported in other studies, which confirmed that the effects of having a person with mental illness in the family not only affected carers but also other family members and that people around them began to treat them differently (Badger, 1996). However, in this study the role of immigration exacerbated the social effects of caring for a person with mental illness. Families in this study were more isolated from the outside world due to cultural and linguistic factors. This was mainly related to the effects of immigration such as loss of extended family who could have provided the major source of both emotional and financial support to the carer. Due to the closeness and reliance of family members on each other, immigrant Egyptian families would be reluctant to ask for help from outsiders, thus reducing or limiting their social contacts with the outside world. This left families isolated and lonely. Issues of trust and the fact that it is hard for Egyptians to trust someone outside the family also limited their social contacts with others.

At the family level, the experience disrupted the quality of relationships between family members and the relationships outside the family. The majority of participants revealed that their relationships with the rest of the family were dramatically affected after their relative became mentally ill. This disruption was due to the difference in levels of tolerance of the behaviour of the person with mental illness among different family members, and to the possessive behaviour of the person with mental illness. The social isolation many participants found themselves in was also related to the
stigma associated with mental illness. Participants were very secretive about mental illness because they believed it was a family matter which should be dealt with in the family. Their lack of trust of people outside the family coupled with the stigma associated with mental illness also reduced their social interactions. Blaming and labelling the family as dysfunctional and a contributing cause to the illness led participants to avoid and escape criticism, and so they were left alone and lonely, even separated from the rest of their family. A number of participants reported that other family members blamed them for causing the mental illness.

Immigration and loss of extended family does not only affect carers’ coping and resilience, but also the person with mental illness. In Egypt, especially in the countryside, families socialise the persons with mental illness with extended family members, and involve them in agricultural activities, which provide venues for the persons with mental illness to socialise with others. Families tend to normalise and create the living conditions that will help the persons with mental illness to get better and rehabilitate. Socialising the person with mental illness with others would not only help them to get better but reduce the negative effects of mental illness such as the withdrawal behaviours (Okasha, 1988). This in turn, relieves families and carers for a period of time from the demands of caregiving, thus reducing carers’ and families’ stress. It gives them the opportunity to have free time for themselves to relax or socialise with others. In contrast, in Australia, where people’s life styles are different, and a large number of persons with mental illness have no carers/family involvement (Roming & Rowland, 1990), persons with mental illness are left alone and separated from their extended family for different reasons, thus putting them at a higher risk of deterioration in their mental health especially of negative symptoms such as withdrawal.

A common view expressed by participants, especially those who had immigrated to Australia as adults and who had experienced what it was like to be among friends and family and how people viewed and dealt with mental health problems in Egypt, was that being an immigrant with very limited professional and social support was one of the major factors contributing to their stress. A number of participants compared their lives before and after immigration and the roles friends, neighbours and extended
family in Egypt played not only in their social lives, but also in other aspects of surviving and coping with adverse life events.

Many participants expressed that if they had experienced the same situation in Egypt, the effects of caring for a relative with mental illness would have been less stressful. This is because, in Egypt, they would have shared the responsibility of caregiving among other family members who had the time and commitment to provide care. It would be a shared responsibility rather than the responsibility for caring left in the hands of one or two people only, to bear all the burden on their own. They compared this to the lifestyle in Australia, where everyone was always busy, and people kept to themselves and were not interested in being involved with families who had a relative with mental illness. Participants also revealed that the family was the main source of support and comfort in time of need in Egypt. The active social life in Egypt acted as a buffer to stress for many Egyptians. In Australia, they missed the family life and family cohesiveness. They felt isolated and lonely, carrying the burden alone. Despite everything, Egyptian families caring for a person with mental illness learned to cope with the burden of caregiving. They realized that they had to cope and continue caring for their loved ones as no one else would do this. Carers found themselves the only people their loved ones relied on. As mentioned earlier, because it is an expected practice among Egyptian families to care for their ill persons and not to abandon them, this reliance helped them to endure, cope and accept the caregiving role.

5.10 IMMIGRATION AND INTERGENERATIONAL DIFFERENCES

Intergenerational difference was evident in the way participants viewed mental illness. Younger generations had attitudes and beliefs about the nature and cause of mental illness which were different from those of older generations. This could be due to cultural differences. Specific to the current study, some participants had migrated to Australia as adults, thus they had acquired Egyptian ways of thinking and behaving, which were different from those participants who migrated to Australia as children or who were born in Australia, thus acquiring more Australian ways of thinking. Older generations attributed mental illness to the evil eye, evil spirit possession and to magic, in spite of the fact that they came from different social classes. This finding was contrary to previous studies, which showed that only people
from middle and low social classes believed in these causes (El-Islam, 1982; Okasha et al., 1994). On the other hand, younger generations related mental illness to purely scientific and/or environmental factors. Participants who came young to Australia (representing the Western culture) had a different understanding of the nature of the illness compared to older generations (representing the Eastern culture). Findings of this study showed that there were differences in the way families viewed mental illness. This difference can be related more to cultural factors than the social class factor found in other studies.

Furthermore, intergenerational difference was evident in the way family members reacted to mental illness. Younger generations were more accepting of the idea of hospitalisation of the person with mental illness, unlike older generations who were more reluctant and opposed to this idea, considering it as abandoning their loved ones. It was mainly the siblings of the person with mental illness who were open to the idea of letting their loved ones receive help through institutionalisation/hospitalisation, as opposed to parents, especially mothers, who rejected this idea. This intergenerational difference could be due to the different perceptions of health services between generations, which reflected a change in perception across generations, impact of immigration and culture difference.

5.11 CONCLUSION

This chapter discussed the main issues facing Egyptian families caring for a relative with mental illness in Australia. These issues were discussed in line with the literature on caregiving. Consistent with the literature, families in this study were overwhelmed and drained by the experience but despite of that, they continued to care for their loved ones. Within Egyptian culture, caring was a shared responsibility among family members and for religious and cultural reasons, families did not abandon their loved ones. However, there were intergenerational and intercultural differences between siblings of people with mental illness and parents in the way they viewed and dealt with mental illness. Families’ need for support and information from health care professionals was evident in this study and in the literature. Families used a variety of strategies to survive the experience, such as spirituality, remembering good times, coming to terms with reality and being more accepting. Though families in this study had much in common with other families mentioned in
the literature, they also had their unique experiences in the way they viewed and dealt with mental illness, which was influenced by Egyptian tradition and culture. Mental illness was highly stigmatised among Egyptian families which resulted in a delay of accessing mental health services and increased families' isolation. Families' isolation was exacerbated by immigration due to loss of extended family, friends and neighbours who would have been a major source of support for many Egyptian families. In conclusion, caring was found to be a universal act across all cultures and families, but has a unique meaning to each person living the experience of caregiving. Findings of this study suggest that there are similarities and differences between and within cultures.
CHAPTER 6

SUMMARY AND RECOMMENDATIONS
6.1 INTRODUCTION
This chapter ties the participants’ stories to the original query into the lives of the Egyptian families living in Australia who are caring for a relative with mental illness. The last two chapters brought us to the discovery of the Egyptian world and shed some light on the ways families experience everyday practices. This chapter brings us back to the beginning of the hermeneutic circle and where we started the inquiry. The following section provides a brief overview of the study and its findings and how these findings are related to and answered the research question. This is followed by the implications of the findings of the study for nursing practice, mental health services and nursing education. The strengths of the study are outlined, followed by limitations of the study. Finally, recommendations for future research are discussed.

6.2 CONCLUSIONS
Though the impact of caring for a relative with mental illness has been documented in the literature, there is a lack of studies examining the caregiving experience among Egyptian families living in Australia. This study has attempted to fill in gaps in the literature and to shed light on the lives, practices, beliefs, attitudes, feelings, thoughts, and ways of coping with caring for a relative with mental illness in Egyptian families.

The study, guided by Heideggerian phenomenology, has examined what it is like to have a person with mental illness in Egyptian families in Australia. The findings of the study suggest the following:

- Caring for a relative with mental illness can be overwhelming and can have devastating effects on the primary caregivers as well as on the rest of family.
• The effects of immigration, such as loss of extended family, loss of social support and loss of social status, appeared to increase carers’ stress and feelings of loneliness and helplessness.

• Families were drained physically, emotionally, mentally, spiritually, socially and financially, leaving them feeling confused, powerless, helpless, worried and uncertain of the future.

• Families were shocked with the diagnosis of mental illness. Some lived in disbelief and others did not take it seriously until symptoms were severe.

• The behaviour of the person with mental illness was a source of embarrassment to the rest of the family, resulting in family members becoming more isolated, alone and lonely.

• Having a person with mental illness caused disruption between family members: disruption between husband and wife, between siblings and between siblings and parent.

• Families experienced feelings of blame. They blamed God, self, parents, the person with mental illness, the medication, the evil eye, magic and evil spirit possession.

• Families’ protection and care for their loved ones took place in two settings: the home and the hospital setting. Families’ care for their loved ones was born of a single or of a mix of reasons: love, duty, obligations, religious beliefs, family traditions and upbringing.

• In the hospital setting, families’ experience with the health care system varied. At times, families were satisfied with the care their loved ones received and the way health care professionals communicated with and showed concern and empathy for families. At other times, families experienced dissatisfaction and frustration, mainly because health care
professionals did not involve them in the care of their loved ones, did not provide them with adequate information about the illness, its prognosis and the management of the person with mental illness.

- Families developed coping skills over time. They gained better coping skills over time compared to their initial experience in caring for their loved ones. This was because families learned what worked and what did not work by experience and years of caring for their loved ones.

- Spirituality, being close to God and going to church, was the main source of support to Egyptian families involved in this study. Families tended not to access mainstream support groups due to language barrier, stigma and lack of trust of people outside the family.

- In order to survive, families hoped for a miracle, they remembered good times shared with their loved ones in the past, they learned to endure and accept the realities of their situation. Some families compared their lives to others, which helped in accepting their situation, and finally some caregivers sought professional help.

6.3 IMPLICATIONS OF THE STUDY FINDINGS

6.3.1 Implications for Nursing Practice

- The findings of this study can be used to inform mental health nurses, as well as other disciplines, of Egyptians’ ways of viewing and coping with mental illness. This in turn can increase the nurses’ confidence when dealing with clients and families from Egyptian and similar cultural backgrounds. This study has the potential to increase staff awareness of the similarities and differences between cultures and the need to be actively involved in seeking knowledge of other cultures in order to be better equipped to provide culturally sensitive care to clients and families who come from a culture that differs from theirs.
• The findings of this study showed that some families lacked adequate information about mental illness and how to deal with their mentally ill relative. This included lack of knowledge about the diagnosis, the symptoms of mental illness, and what to expect or not to expect from the mentally ill person. Therefore health care professionals, particularly nurses, need to either provide direct support to families and carers of people with mental illness by providing practical and relevant information or by referring them to appropriate services that will meet their needs. Nurses need to convey concern and interest in answering questions raised by families, be patient with them, be there for the families, and be able to listen to their concerns with empathy and respect for their feelings.

• Findings of the study showed that the caregivers themselves were at high risk of developing mental health problems such as depression, and/or physical problems in their lives as a result of caring for a relative with mental illness. This has an implication for community mental health nurses who have access to the patients’ homes, and families. Nurses have the skills to identify those caregivers who are at risk of developing mental illness and provide them with either direct support and care, to help them cope with the caregiving role, or refer them to the appropriate services to meet their needs. Community nurses can play an important role in health promotion, and illness prevention strategies among families of the mentally ill.

• The use of inappropriate interpreters was a factor for families’ dissatisfaction with the mental health services. It was reported that using interpreters from a different cultural background caused confusion and misunderstanding between clients and health care professionals in the interpretation process, especially when the interpreter spoke a different dialect from that of the clients. It is recommended that nurses and other health care professionals use interpreters from the same cultural background of clients as much as possible to improve communications with clients and families, hence increasing their satisfaction.
• The majority of Egyptian families reported the use of spirituality as a coping strategy with the stressors associated with caregiving. Many families hoped for a miracle to happen and had faith in God. Nurses, in providing care for clients, should be able to provide holistic care, recognising the important role of spirituality in providing hope, coping and resilience. Therefore, nurses need to work in partnership with religious leaders and traditional healers in a shared care approach, to ensure the clients’ spiritual needs are met. This can be done by reaching out to minority groups such as Egyptians and providing community education, which can be facilitated by involving religious leaders.

• It was reported that the caregivers suffered financial problems as a result of the delay in providing financial services. As nurses provide holistic care for the patients and their families, and work within a multidisciplinary team, they can collaborate with social workers in helping clients and families to access their entitlement for financial assistance.

6.3.2 Implications for Mental Health Services

• Families reported ‘being left out’ in the mental health system. Therefore, services need to cater for not only carers of people with mental illness, but also for the rest of the family by using a family-focused approach to care and by involving families in the care provided to their loved ones.

• This study has implications for the wider community in terms of addressing and reducing the stigma associated with mental illness and its adverse effects on the persons with mental illness and their families. Services should provide education and mental health promotion not only to consumers and families, but also to the wider community through the media and community forums to help change societal attitudes towards mental illness and the stigma associated to it.
- To reduce families' confusion and distress, information and education, carer counselling, carer skills training and respite services for carers are needed.

- Families' needs varies, and some families may not be interested to join support groups, therefore, mental health services could reach out to these families in a way that would be more accepting and less threatening, for examples, by using local media for providing information and indirect support.

- To improve the quality of services provided to people from CALD backgrounds, services need to ensure that their interpreters be adequately trained in mental health to ensure accuracy of interpretations of mental health issues.

- There is also a need for culturally and linguistically appropriate services that will meet the cultural needs of clients and families who come from CALD backgrounds.

6.3.3 Implications for Nursing Education

- Nurses need to be adequately prepared and trained in cross-cultural nursing in order to provide culturally sensitive care to clients and families who come from CALD backgrounds. Nursing education should prepare nursing students with the skills and knowledge that will enable them to work effectively with people from CALD before they enter the workforce.

- Education should be provided by nurses who come from different cultural backgrounds so that their knowledge can help other nurses to be aware of the characteristics of specific cultures. For example, a nurse who comes from a Chinese background can help other nurses and other health care professionals to be knowledgeable about the Chinese culture and how to approach and care for Chinese clients effectively. Again, a nurse from an Arabic background could help other staff to learn about the Arab culture
and so on. This could be achieved through in-service sessions or multimedia including pamphlets and videos.

- In-services on the use of interpreters are needed to help nurses and other mental health care professionals work effectively with interpreters, clients and families from CALD backgrounds.

6.4 STRENGTHS OF THE STUDY

- After reviewing the literature on caring for a person with mental illness among families who come from diverse cultural and linguistic backgrounds, no study was identified that had examined Egyptian experiences of caring for a relative with mental illness in Australia. This study brings to light the caregiving experience as expressed by Egyptian families living in Australia and the factors that influence the way families live and interpret their caregiving experience. The significance of this research lies in its ability to identify the carers’ needs, in an attempt to reduce the stress of caring for a relative with mental illness, thus reducing the carers’ risk of developing mental health problems.

- Hermeneutic phenomenology has much in common with nursing practice and nurses’ philosophical beliefs, in that it respects the individuality of the person, views the person as self-interpreting, focuses on the subjective experience of people, and deals with the person in a holistic manner. By relating the phenomenological concepts to the current study, the experience of caring for a person with mental illness was studied in a holistic way, focusing on the social, cultural, historical, and physical context in which this experience took place; and at the same time it looked at the subjective and unique experience of caregiving of Egyptian families living in Australia.

- The method used in hermeneutic phenomenology allowed the participants in this study to express themselves freely and getting their voices, concerns
and needs to be heard and becomes visible. Thus, the study has the potential for influencing policy making and community development.

- This study explored many cultural issues, which can give nurses a deeper understanding of a culture of which little is known, in terms of its values, beliefs, practices, and needs. The outcome of such understanding will benefit both nurses and families in building a therapeutic relationship, in reducing cultural conflict, and in providing culturally sensitive care.

- This study explored the experience of caregiving among different family members. Participants were either a mother, husband, wife, daughter, sister or a brother; these differing experiences have not been explored in other studies. This variety allowed the voices of different people to be heard in one study. Most research has focused on either mothers as carers (Doornbos, 1997; Mohit, 1996; Provencher, 1996; Tuck et al., 1997) or spouses as carers (Badger, 1996; Eakes, 1995), but not siblings as carers. The findings of this study have a significant impact on understanding how family members react differently to the person with mental illness. Consequently, health care professionals should be familiar with differences in roles and relationships and how these might impact on the well-being of different family members; they should recognise the necessity to provide support to meet the different needs of different family members.

6.5 LIMITATIONS OF THE STUDY

- Some of the limitations of the study are identified in the methods chapter and are related to the difficulty in accessing Egyptian families who are caring for a relative with mental illness. This was due to stigma associated with mental illness and the Egyptians’ reluctance to ask for help outside the family. Also Egyptians are protective of their own privacy in general, which in this case was heightened due to the subjectivity and sensitivity of the topic under study. As a result, only one of the seven participants was from a different religious background. If participants had represented a
mix of religions, the study would have given a deeper understanding of the role played by different religions in the way families experience and cope with caregiving.

- It could be argued that more participants should have been interviewed; however, due to the above mentioned factors as well as the unfamiliarity of the Egyptian people with research, their suspiciousness of people collecting data or doing research and general trust factors, the number of the participants was limited to seven. Considering the aim of the study, which was to discover the world and the experience of caring for a relative with mental illness, rather than generalizing the findings, the limited number of participants in this study is considered acceptable. This is due to the depth and breadth of the knowledge and understanding gained through the participants’ stories, and the meaning of care, which this study unfolded.

- The study aimed at exploring the caregiving experience with more than one family member. However, due to the limited number of participants who agreed to take part in the study and the reluctance of other family members to participate in the study because of issues of stigma, this process was hindered. However, family members did reveal intergenerational differences in the way they viewed mental illness and in the way they related to the person with mental illness. This study interviewed two members of the same family. There is a need to explore the caring experience among other family members, to identify any similarities or differences in the way different family members view and cope with caring for a member with mental illness in order to identify their future needs.
6.6 IMPLICATIONS FOR FUTURE RESEARCH

- The difficulty that faced the researcher in accessing Egyptian families raises many questions that need to be answered in future research. Research is needed to reveal the reasons that prevent people from participating in research and how this can be overcome so as to ensure that research studies are equally culturally diverse.

- This study has shown that caring for a person with mental illness is culturally specific and therefore more research is needed in order to increase our knowledge and understanding about other cultures’ beliefs, values, practices and needs to ensure those needs are being met.

- This study has shown that exploring the lived experience is an excellent way of providing insight into cultural differences in caring for a relative with a mental illness. Future studies could use this study’s method to explore other cultures and mental health to determine their specific needs. Further studies are also needed to determine the impact of migration by comparing the lived experience of Egyptian families (or any other culture), caring for a relative with mental illness and who are living in Australia compared to families living in Egypt.

- Further research is needed to address and examine families’ strengths and the positive aspects of the caregiving experience, and the positive influences and input of the person with mental illness person, that is, how the mentally ill person contributes to the family.

- Though there are similar problems encountered by carers among different cultural groups, there is a need for different approaches to solutions to make care culturally relevant. Therefore, we cannot generalize the findings of any study and assume it will fit and address the needs of all ethnic groups living in Australia.

- Future research could compare and contrast the findings of this study with other studies dealing with similar or different cultures. Replication of the study
could be undertaken to provide more knowledge about a specific culture of which little is known.
APPENDIX

Information Sheet

Dear potential participant
My name is Gihane Kamal Endrawes. I am a Clinical Nurse Consultant, working at Liverpool Hospital. Currently, I am doing a PhD in Nursing at the University of Western Sydney, Nepean. In order to achieve this, I am conducting a research study about the Egyptian families who are caring for a relative with mental illness. Therefore, I would like to invite you to take part in this study. This study has been approved by the Ethics Committee at the University of Western Sydney. The approval number is HE 99/013 and the title of the study is “Mental Illness, Egyptian Families Caring for a Relative with Mental Illness in Australia”.

If you agree to participate in the study, you will be interviewed by myself for about an hour to an hour and a half at the beginning of the study. A need for a second brief interview may be required in the future to clarify any issues that were not clear at the first interview. You will be given the choice to use the Arabic or English language. You will be asked to talk about your feelings, thoughts and attitudes about caring for a mentally ill relative, how you cope with the experience of caregiving. This will help us as nurses to identify the family’s needs and to find ways to meet these needs in a culturally sensitive manner. You can choose the place you would like the interviews to be conducted in. The interviews will be audio-taped for later use in the study. All the information you give is very confidential, privacy and anonymity will be maintained throughout the study. In addition, you have the right to refuse or withdraw from the study at any time without any penalty or being disadvantaged. The personal identifying information obtained from the interviews will be destroyed five years after the completion of the study. Due to the nature of this study, some emotional discomfort may be experienced, therefore the following counselling services are available on request:

- Carers’ Support Group - At the Transcultural Mental Health Centre, Tel: 98403901
- Merrylands Community Health Centre: Ms Ellan Salama (Psychologist), Tel: 96823133

Please do not hesitate to ring me on (02) 96365240 for further information.

Yours faithfully
Gihane Endrawes
REFERENCES


Saout El-Moughtareb. To whom it may concern in the Arabic community, 7 December, 1989, p. 11.


Egyptian Families Caring for a Relative with Mental Illness in Australia

G. ENDRAWES

A THESIS SUBMITTED IN TOTAL FULFILMENT OF THE REQUIREMENT FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

UNIVERSITY OF WESTERN SYDNEY

2003
CERTIFICATE

I certify that this thesis has not been already been submitted for any higher degree at any other institution.

I also certify that this thesis entitled *Egyptian Families Caring for a Relative with Mental Illness in Australia* and submitted for the degree of Doctor of Philosophy, is the result of my own research, except where otherwise acknowledged.

Signature of Candidate

.............................................

Date

.............................................
PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

and the best possible result has been obtained.
ACKNOWLEDGEMENTS

Dr Louise O’Brien for sharing her expertise, and for her ongoing support and patience.

Professor Lesley Wilkes for sharing her expertise, and for constructive criticism and support.

The families who participated in this study, for the time and stories they shared with me.

My husband Medhat Endrawes for believing in me, his never ending support and encouragement.

My daughters Clara Endrawes and Amanda Endrawes for their love, care, support and understanding.

My parents for their prayers, love and support.
# TABLE OF CONTENTS

**Certificate** .............................................................................................................. ii  
**Acknowledgement** ............................................................................................... iii  
**Abstract** .................................................................................................................. vii  

## CHAPTER 1  INTRODUCTION TO THE STUDY

1.1 Introduction ........................................................................................................... 2  
1.2 How I Became Interested in the Issue Under Study ........................................... 2  
1.3 The Research Question ......................................................................................... 3  
1.4 Significance of the Study ....................................................................................... 4  
1.5 An Outline of the Thesis ....................................................................................... 4  
1.6 Summary .............................................................................................................. 6  

## CHAPTER 2  LITERATURE REVIEW

2.1 Introduction ........................................................................................................... 8  
2.2 Culture and Health ............................................................................................... 8  
2.3 Migration and Mental Illness ............................................................................... 12  
2.4 Egypt ..................................................................................................................... 15  
2.5 The Egyptian Culture and Communication ....................................................... 16  
2.6 The Egyptian Family ........................................................................................... 18  
2.7 The Egyptian Culture and Mental Illness ............................................................ 22  
   2.7.1 Services ......................................................................................................... 22  
   2.7.2 Attitudes to Caring in the Family .................................................................. 24  
   2.7.3 Folk Beliefs and Practices ............................................................................ 26  
2.8 The Experience of Caregiving ............................................................................. 31  
   2.8.1 Chronic Sorrow ............................................................................................ 32  
   2.8.2 The Burden of Caregiving .......................................................................... 34  
      2.8.2.1 Gender and the level of burden ............................................................. 37  
      2.8.2.2 Age of carer and the level of burden .................................................... 39  
      2.8.2.3 Diagnosis of mental illness and the level of burden ............................ 39  
      2.8.2.4 Effects of burden on family relationships .......................................... 40  
2.8.3 Burden of Negotiating Health Services ......................................................... 41  
2.8.4 Strategies for Survival ..................................................................................... 42  
2.9 Summary ............................................................................................................ 47  
2.10 Research Aims ................................................................................................... 48  

## CHAPTER 3  THE RESEARCH PROCESS

3.1 Introduction ......................................................................................................... 51  
3.2 Research Design ................................................................................................ 51
CHAPTER 4    THE EXPERIENCE

4.1 INTRODUCTION .................................................. 73

4.2 INTRODUCING THE PARTICIPANTS ............................. 73
   4.2.1 Peter George ................................................. 73
   4.2.2 Farah Mina .................................................. 73
   4.2.3 Sarah Mina .................................................. 74
   4.2.4 Sam Emile ................................................... 74
   4.2.5 Rhonda Farouk ............................................. 74
   4.2.6 Andrew Silver .............................................. 75
   4.2.7 Rosa Morcus ............................................... 75

4.3 THEMES - THE STORIES UNFOLD ................................ 78
   4.3.1 Why Did It Happen? ......................................... 78
       4.3.1.1 Being shocked ........................................ 78
       4.3.1.2 Blaming ................................................. 78
   4.3.2 How Do I Protect My Loved Ones? ........................ 80
       4.3.2.1 Protecting at home .................................... 80
       4.3.2.2 Protecting in the hospital setting .................... 81
   4.3.3 What Has It Done To Me? ................................... 83
       4.3.3.1 Being drained .......................................... 83
       4.3.3.2 Sacrificing my own dreams, freedom and future .... 91
       4.3.3.3 Losing my identity/role ................................ 93
   4.3.4 What Has It Done To Us? ................................... 94
       4.3.4.1 Living in isolation ...................................... 94
       4.3.4.2 Change in the relationship with family and friends .... 96
   4.3.5 How Do I Survive? ........................................... 98
       4.3.5.1 Living in hope .......................................... 99
       4.3.5.2 Remembering good times .............................. 100
       4.3.5.3 Enduring and accepting the realities .................. 101
       4.3.5.4 Seeking professional help ............................... 102

4.4 SUMMARY .......................................................... 102
CHAPTER 5  DISCUSSION

5.1 INTRODUCTION .............................................................................................................. 105
5.2 BEING DRAINED AND OVERWHELMED ............................................................... 105
5.3 WAYS OF CARING ......................................................................................................... 106
5.4 EXPERIENCE WITH THE HEALTH CARE SYSTEM .................................................. 107
5.5 WAYS OF SURVIVAL .................................................................................................... 108
5.6 TRADITION AND RELIGION ......................................................................................... 110
5.7 SERVICE UTILISATION .................................................................................................. 111
5.8 STIGMA ........................................................................................................................ 113
5.9 IMMIGRATION AND ISOLATION .................................................................................. 114
5.10 IMMIGRATION AND INTERGENERATIONAL DIFFERENCES ............................... 116
5.11 CONCLUSION .............................................................................................................. 117

CHAPTER 6  SUMMARY OF THE STUDY AND RECOMMENDATIONS

6.1 INTRODUCTION .............................................................................................................. 120
6.2 CONCLUSIONS ................................................................................................................ 120
6.3 IMPLICATIONS OF THE STUDY FINDINGS ................................................................ 122
   6.3.3 Implications for Nursing Practice ......................................................................... 122
   6.3.3 Implications for Mental Health Services ................................................................. 124
   6.3.3 Implications for Nursing Education ........................................................................ 125
6.4 STRENGTHS OF THE STUDY ....................................................................................... 126
6.5 LIMITATIONS OF THE STUDY ...................................................................................... 127
6.6 IMPLICATIONS FOR FUTURE RESEARCH ................................................................. 129

LIST OF TABLES
   TABLE 1 – THEMES AND SUB-THEMES ........................................................................ 76

REFERENCES ....................................................................................................................... 131

APPENDIX
   INFORMATION TO PARTICIPANTS ................................................................................. 159
ABSTRACT

The meaning of caregiving for a relative with mental illness has been explored in many research studies; however, there is a lack of studies on the caregiving experience within the Egyptian culture. This study aimed at getting closer to Egyptian families caring for a relative with mental illness in Australia in order to reveal how these families live and cope with mental illness, their attitudes, beliefs and practices and how the experience affected them. Qualitative hermeneutic phenomenology informed by the work of Heidegger was used. Seven participants from Egyptian background, caring for a relative with mental illness, participated voluntarily in this study, and were informed of their rights. Access to participants was through advertising, referral from psychiatrists and community centres. Data were collected through in-depth interviews, which lasted between 1½-3 hours. All interviews were audio-taped. A content check with some interviewees was done to clarify certain issues that were unclear. The interviews were conducted in the Arabic language, which were then translated and transcribed in English. Each interview was read several times, then each section was summarised. The transcripts were read again while listening to the audio-tapes to ensure accuracy of meaning. All interviews were compared to each other, and five (5) common themes were identified: Why did it happen? Participants were shocked by the diagnosis and blamed God, self, others, the person with mental illness, the medication, the evil eye, magic, and evil spirit possession. How do I protect my loved ones? Protection was due to love, duty, religious beliefs, family tradition and upbringing. Participants’ satisfaction and dissatisfaction with the health care system varied. What has it done to me? Participants experienced physical, emotional and financial drain, sacrificing their dreams, freedom and future, and experienced loss of identity. What has it done to us? The experience left them isolated and lonely and disrupted many relationships with others. How do I survive? Living in hope, remembering good times, enduring and accepting the reality, and seeking professional help have assisted participants to survive. Findings of the study have the potential to raise health care professionals’ awareness of the needs of Egyptian families, their beliefs, values and coping with mental illness. Further research is needed to reveal families’ strengths in caring and the positive outcomes of the caregiving experience. Strengths and limitations of the study are also presented to inform future research.