SCHIZOPHRENIA IN THE FAMILY:

STUDYING THE EXPERIENCE OF CAREGIVING

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A DISSERTATION SUBMITTED
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR
THE DEGREE OF MASTER OF SOCIAL SCIENCE (SOCIOLOGY)
NATIONAL UNIVERSITY OF SINGAPORE
2007

Acknowledgements

The following people have been pivotal to the painstaking research, construction and completion of this thesis, and it is to them that I owe a debt of gratitude.

My advisor, Professor Stella Quah, whose invaluable guidance, kindness and patience made this possible.

The tireless and noble people at the Singapore Association of Mental Health: the director Ms. Rajesweri K. who permitted me to do my research at the SAMH, and social workers Ms Rachel Goh and Ms. Za Elisabeth who welcomed me to the Club 3R with their warmth and support. I am especially grateful to Rachel for her guidance and help throughout my fieldwork at the FLP.

My friends and colleagues, Lisa, Soon Hock and Kai Chong, who shared a similar journey, and whose presence made mine all the more meaningful.

Adisak, who, by serendipity and wisdom, helped save this thesis from its near death.

Finally, the twelve people whose stories made this thesis possible: their journeys have changed my perspective on life in profound ways, and left me with the utmost respect for each of them.

Vivien Won
May 2007

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Summary

This thesis examines the process of coping among twelve individuals who are caregivers of a close family member affected by a chronic mental illness. I adopt a sociocultural perspective from medical sociology to explain the strategies that caregivers use to cope with schizophrenia in the family. Dimensions of coping include the recognition mental disorder in a loved one, the different choices that are taken in the search for treatment, and the management of the patient in everyday life. I explain how social support, kinship and other informal social ties, information, beliefs and values, shape the struggle, adaptation and managing of difficulties which characterise the social process of giving care. My thesis argues that family caregivers respond to mental illness using different illness meanings to interpret signs of disorder to seek treatment for their afflicted kin. Although all the caregivers use the formal psychiatric treatment system and accept the biomedical model of mental illness as an illness meaning they subscribe to and use other frameworks of interpreting illness and recovery in the care of the mental patient. (In the struggle towards establishing normality in the afflicted individuals' lives, caregivers marshal different strategies to deal with the host of problems in the care of a loved one.)

Respondents were recruited from a community mental health organization where I worked as a volunteer-facilitator. I conducted participant observation in a caregiver support group for six months and carried out between two to three in-depth interviews with each respondent using a semi-structured interview approach.

CHAPTER ONE

INTRODUCTION

This study is tasked to understand the social dynamics of mental illness caregiving: how lay persons identify “abnormal” behaviour as a disorder of the mind, their strategies for seeking help and coping with the problems that follow a definitive psychiatric diagnosis of schizophrenia in their loved ones. Knowledge and understanding of coping behaviour has practical value for the health status of mental health sufferers and their caregivers. Under special circumstances like severe mental illness, retardation or physical debilitation, caregiving is transformed from a quotidian exchange of assistance amongst people connected by kinship or marriage into an extraordinary and unequally distributed burden. The cost of caregiving extends beyond financial burden to elevated levels of physical and emotional strain on those who provide informal care within the home and community (Zarit, 1989; Horowitz, 1985a).

With the deinstitutionalization of mental hospitals (Cook and Wright, 1995), emphasis has shifted towards community-based care and rehabilitation with a larger proportion of services devolved to support organizations and networks in the community rather than the psychiatric hospital. More patients who are grappling with psychotic symptoms live and work in the community. In Singapore, responses to the needs of the elderly, the sick and invalid relies greatly on the domestic sphere, and nearly 90% of schizophrenia patients live with their family (Tan et. al. 2004). As people confront health and other problems in their lives, family members typically take on this supportive role. The latest mental health population survey revealed a low preference for seeking formal treatment for mental illness as well as underreporting of a mental health problem amongst respondents who were identified as being psychiatric cases (Ng, et. al. 2003). The prevalence rate for minor psychiatric morbidity in Singapore stood at 16.6% in 1998 (Fones, et. al. 1998). This implies that those suffering from a mental illness remain oblivious to their condition or reluctant to seek help until symptoms become severe. The onus to seek treatment usually falls on a close family member, and even so, this process may be fraught with ambivalence and anxiety. Decisions to seek help for mental illness and managing a mentally ill loved one are bound up with issues of social stigma. In a community survey of social attitudes, one in four (26.7%) respondents thought that people suffering from depression have "only themselves to blame" for their condition; two out of three (65.5%) respondents believed that depression is a condition in which the use of personal willpower was an available option to those who were afflicted (cited in Yeo, 2003). Our society is one in which self-help and self-determination are highly-prized characteristics of the citizenry and mental illness is still very much stigmatized or believed to be caused by some moral deficiency (Lai et. al., 2001).

There is still a dearth of research looking into the experiences and welfare of caregivers in Singapore. The most recent work was Seng's (2005) cross-sectional study which explored factors contributing to caregiver strain. However, the complexity of caregivers' experiences cannot be fully depicted by measures of burden or well-being; I contend that tension and ambivalence are rife in illness management, particularly in choices of alternative actions for securing needed support and care for the myriad problems that beset each schizophrenia patient. Formal support services in mental health are still very much in the background, with a few voluntary welfare organizations being the main providers. How is mental illness recognized by a lay person? What modes of treatment (if any) are chosen by a close family member? What are the social dynamics of obtaining and providing care for a patient? It is thus useful to explore the patterning of care arrangements and coping behaviours which mediate the impact of stress and hardship upon individuals who provide long-term, often round-the-clock care to a loved one.

It is ideal to explore the important role that the formal healthcare sector plays in questions that concern identifying and coping with severe mental illness in the family. Kleinman (1980) convincingly drew attention to the critical role of formal healthcare providers and other researchers have studied this effect on caregiving outcomes. However, the focus of this thesis is on the family of a schizophrenia sufferer, and not on exploring or assessing how formal support aids the caregiver.

Having presented the rationale and relevance of studying caregivers of schizophrenia patients, I will continue with a review of the literature in this field. The rest of this chapter consists of three sections. The first is an overview of the concepts pertinent to schizophrenia, and the complexities involved in the study of caregivers of schizophrenia sufferers. The second section reviews the main theoretical perspectives, including how previous literature has steered the development of my research. I present my conceptual framework in the final section with detailed clarification of the variables I have selected.

1.1 Studying Caregivers of Schizophrenia Sufferers: Conceptual Overview

1.1.1 Defining Caregiving

Coping behaviour can be considered one of the most important variables in health and family stress research. The needs of schizophrenia patients are contingent to a large extent on the ability of their immediate family to provide the long–term maintenance treatment and rehabilitative care that they require. “Caregiving” refers to the behavioural expression of commitment to the protection or enhancement of a relative’s well-being (Pearlin et. al. 1990) and encompasses activities that provide help or support to a family member who requires specific types of help. Caregiving is embedded in what Cooley (1909) described as primary relationships, hence it occurs in the actions and contexts of established family roles, such as spousal and intergenerational relationships. The heterogeneity of caregiving relationships poses a methodological issue to studying those who give care. Zarit (1994) showed that the kinship relation between caregiver and recipient, whether they co-reside or live separately, the baseline severity of the patient’s condition as well as the health, socioeconomic status, and ethnicity of the caregiver will affect the different facets of giving help and support. On top of these varying conditions, some patients may need help with instrumental tasks like managing their finances and activities of daily living while others can function with relative independence and only require minimal supervision. Horowitz (1985b) found that one family member generally occupies the role of primary caregiver when the need arises. However, there may be more than one family member who assists differently and who consider themselves caregivers, while a primary caregiver with the major responsibility for this role may not consider oneself anything more than a mother or husband doing what is otherwise normal or obligatory in the capacity of that role.

Bearing this in mind, the subject of my study may not be the sole provider of care to a loved one, due to the multitude of differences in caregiving relationships and families. However, the variation in types of help rendered and how this is distributed between different family members points to the fact that coping strategies differ depending on the role played – be it a spouse, parent or sibling. Caregiving does not happen in a vacuum as members of a family would respond together albeit in different ways in order to cope with adversity. Sources of help or social support may attenuate the burden of care on the primary caregiver. The provision of assistance, in however large or minor a capacity, is done in the context of a transformation in ongoing patterns of exchange in response to the family member who is ill.

Another important issue related to studying caregivers concerns delimiting when the actual giving of care begins. In many families of the mentally ill, coping repertoires are likely to have been called upon before the imposition of a medical diagnosis, and many people continue to cope with and give care to someone who has never been treated for a mental illness. The subjects in this study may have considered themselves as caregivers, or may not have concerned themselves with this official title. However, in keeping with conceptual parameters for research purposes, "caregiving" as a designated role officially marks a turning point in the trajectory of a person's life. The subjects in this study were designated caregivers from the time the patient was formally diagnosed with schizophrenia, because a "caregiver" is a role that denotes a change of status. The caregiver takes on a new set of responsibilities in his or her role vis-à-vis the patient. To avoid confusion when using this conceptual category, I shall use the term "family member” instead of “caregiver” in my analysis of the stages before the psychiatric diagnosis of a patient.

1.1.2 Sufferers of Mental Illness: Conceptual Clarifications

As a disorder of the mind, mental illness manifests behaviourally rather than physiologically. There are many different and opposing theories on mental illness. Proponents of the psychiatric perspective regard schizophrenia as a disease that manifests the same properties as most other physical illnesses (Spitzer, 1976; Wing, 1978). This concept of mental illness refers to patients’ symptoms as a diagnostic category with an established pathology for the purpose of developing laws that explain and predict the occurrence of symptoms and to control these symptoms through psychotherapeutic or pharmacological treatments. One of the most ardent opponents of this view is anti-psychiatry, exemplified by the work of Thomas Szasz (1961) who rejected the validity of psychotic behaviour as illness but merely a function of societal labeling and control. In a similar vein, the social control perspective regards mental illness as a classification of behaviour, rather than the symptoms of illness. It locates mental illness in observers’ categories rather than the actor’s symptoms, and this is aptly exemplified by Scheff’s depiction of mental illness as solely “residual rule-breaking” (1966: 33-34). In his seminal work on the moral career of the mental patient, Erving Goffman (1959, 1961) described the mental patient as one who suffered not from mental illness but from “contingencies” (1961: 135) to the degree that it is not illness per se but the objective structures in one’s social situation as well as the type of social interactions that lead one to hospitalization and eventual labeling as a mental patient.

In addition, the work of cultural anthropologists have drawn attention to the intra-cultural and cross-cultural variability of mental disorders (Kleinman, 1973, 1980; Yap, 1951, 1969; Tan, 1965; Teoh, 1972) further emphasizing that behavioural correlates "do not fit a universal diagnostic grid" (Lefley, 1987b: 107). Hence, what comes to be interpreted as illness rests on the label people attach to culturally recognizable types of deviance, and so interpretation is located in the conventions and understandings that are employed by those responding to the mental patient.

Under what conditions is behaviour deemed a form of mental illness and not some other ontological category and how does this variance explain the search for care? Does "mental illness" reside in a disordered mind, or in the more disordered elements of society? Schizophrenia as a mental illness is often poorly understood and complicated by the ambiguity of what constitutes the state of being unwell (Cockerham, 2001), hence it is not always interpreted or reacted to by lay people as a disorder of the mind. The social control perspective grounds schizophrenia in the categorizations of observers – family members, coworkers, police and community healthcare professionals – which lead to the psychiatric label. What is recognized or perceived as "abnormal" depends on the social context in which the "abnormal" unfolds: the cultural norms of what is acceptable and deviant and the severity of the transgression, all in turn affecting its visibility, and thus the presence and willingness of agents to impose a sanction upon the transgressor. This perspective is valuable because it acknowledges that sanctions against social deviants are not consistently enforced, and the medical labeling of schizophrenics relies on the presence and willingness of actors in the community, judicial and medical institutions to identify the schizophrenic as "abnormal". Vast differences among people in their capacity to tolerate difficult behaviour shapes how each person conceptualizes experiential change differently, moreover it makes identification of deviance (behaviour that is contrary to what is perceived as “normal” by others) more complex (Cockerham 2001).

As a conceptual tool for the purpose of my research, I use contemporary diagnostic criteria from the Diagnostic and Statistical Manual IV (DSM-IV) (American Psychiatric Association, 1994) which views schizophrenia as a genuine disease process. The sociological perspective of mental illness as a social and cultural label is useful because this conceptual approach explains the variation in the social response of observers – a key issue in the pathway towards mental patienthood – while acknowledging that problem behaviours are rooted in psychiatric symptomatology.

1.1.3 Behavioural Manifestations of Schizophrenia

According to the Diagnostic and Statistical Manual IV (DSM-IV), schizophrenia is an objective disease process characterized by a chronic, deteriorating course where there are several stages of disturbances or changes to cognitive, emotional and behavioural functioning (American Psychiatric Association, 1994). Mueser and McGurk (2004) described three broad categories of symptoms: psychotic symptoms (also known as positive symptoms), negative symptoms, and cognitive impairment. A person experiencing psychosis (psychotic symptoms) is unable to differentiate between reality and his own inner world of fantasy. Psychotic symptoms are most commonly manifested as delusions such as having false beliefs or paranoid impulses, and hallucinations which are false sensory perceptions. They characterize the “central feature of psychosis: the impaired and distorted ability to perceive, process and understand the everyday world”.

(Gallagher, 2002:78). Negative symptoms, also known as prodromal or residual symptoms (American Psychiatric Association, 1994), refer to social isolation or withdrawal from social or goal-directed activity; marked impairment in role functioning, personal hygiene; markedly peculiar or erratic speech or affect. The positive or psychotic symptoms of schizophrenia typically erupt with severity and require crisis intervention or hospitalization. The negative symptoms are more persistent throughout the period of mental illness and result in impairment of physical and even cognitive functioning from which the patient seldom recovers (Tsuang, Faraone and Green, 1999).

The experience of caregiving begins at the onset of a psychiatric disorder, when a loved one displays behaviour that is perceived by his family members as abnormal or irrational. Yet mental illness, from the earliest arising of symptoms to its stabilization by mental health treatment, varies widely from person to person. Nowhere is this more apparent than in the schizophrenia disorders (Gallagher, 2002). A caregiver's response might vary according to the severity of the distressing situation, where some states of mental disturbance may be mild, fleeting or even inconsequential to the sufferer while others are likened to a crisis event. Not everyone who encounters schizophrenic symptoms is beset by debilitating symptoms, they more often than not continue with their lives and those around them either live and tolerate the occasional bouts of disturbances. Most significant kin do not identify such incidences as mental illness and fewer might seek help on the patient's behalf. The voluminous literature on how people are led to seek formal healthcare has shown that the "pathway" to formal care is a dynamic one that involves specific events that trigger help-seeking actions (Clausen and Yarrow, 1955; Zola, 1973, Pescosolido 1991; Pescosolido, Gardner and Lubell, 1998).

1.1.4 The Illness Trajectory as an approach to studying Caregiving

The career, typically understood as a developing trajectory of progressive accomplishment, expertise or control in an occupational sphere, has long been used in the sociology of health and illness. As an analytical concept, the career has a long tradition in studies of deviant subcultures (Becker 1953), and its application to the mentally ill is notable in classic studies by Erving Goffman (1961) and Thomas Scheff (1966). More recently, Gerhardt (1990) applied the career concept to the management of chronic illness, Pescosolido (1991) to the utilization of and compliance with mental health treatment, as well as Aneshensal et al. (1993) who documented the career of an Alzheimer's caregiver. In these studies, the illness career denotes a developmental quality to changes and adjustments in the life-course.

Karp (1996) provides a prototypal application of this concept to mental health. He describes the mental illness career as a pathway that entails finding cause, meaning, help, and ultimately coping with what is otherwise a subjective experience of depression. Karp's concept of career looks like a progression through multiple stages of roles and situations, from inchoate feelings of distress towards a commitment to a medical model of mental illness and becoming a mental patient. However, Strauss et. al. (1985) renamed the concept of career to that of "trajectory" to encompass the myriad relationships and work that different actors – hospital staff, community health workers, relatives – put in throughout the course of the patient's physiological illness. In their work, they explain that "trajectory" is a term that refers "not only to the physiological unfolding of a patient's disease but to the total organization of work done over that course, plus the impact on those involved with that work and its organization (Strauss et. al. 1985: 8).

Goffman (1959) astutely noted that the phase before a mental patient is first hospitalized or diagnosed with a mental illness relies on the reconstruction of events that had led to the point of a diagnosis and hospital commitment. Any evidence of signs and symptoms of mental illness during the pre-patient phase exist only because the patient had arrived at the hospital to be assessed if he were mentally ill. A useful study must go beyond the case-history construction that caregivers or other complainants might provide in order to justify the recourse of sending him to the hospital. It should capture as much as possible the multiplicity of pathways and decisions that are taken throughout the search for care. Goffman pointed out that the next-of-kin (the one who most likely becomes the patient's primary caregiver) is the "last to doubt his sanity and the first to have done everything to save him" from this fate (1959: 126). In fact the phenomenology of the illness experience in anthropological studies that address cognition and belief systems address the wide spectrum of behavioural responses to signs of mental disturbance (see Kleinman 1980, Garro 1985). Self care and the use of non-medical alternatives cannot be overlooked. This includes activities such as the initial attempt to self-medicate or self-treat one's symptoms, seeking advice from non-professional family members or those within one's informal social networks (Quah, 2001). Such actions, which may be chosen in favour of consulting a psychiatrist, constitute part of a coping process, a wide spectrum of alternatives that may or may not lead to the psychiatric hospital. The illness experience is located within a social context, or social structure, defined by Rosen and Kleinman (1983) as "a society's institutional arrangement of social relationships". Hence it is necessary to focus on the relationships that are essential to one's ability to cope once illness sets in but before formal treatment is sought.

Therefore, it is necessary to define the boundaries for studying caregivers of patients before they begin their mental illness career. Kasl and Cobb's (1966) term "illness behaviour" refers to actions "taken by persons who are uncertain about whether they are well, who are troubled or puzzled by bodily sensations or feelings they believe are signs or symptoms of illness, who want to clarify the meaning of these experiences and thus determine whether they are unwell, and who want to know what to do if they are not" (cited in Gochman, 1997:5). As this term commonly refers to the goal-directed actions of those who feel ill, it is inapt to apply it on the next-of-kin who are the subject of this study. Hence, "illness behaviour" will be used in reference to the sufferer's actions in the period before diagnosis or hospitalization (or both) while "help-seeking behaviour" will refer to their caregivers and the activities they undertake for the purpose of finding meaning and solutions to their loved one's problematic behaviour.

Defining the behaviour of a mentally ill person after he has been diagnosed presents a sticky complication. Talcott Parsons' (1951) term "sick role" has been widely used to describe someone committed to a treatment regimen dictated by his physician in order to restore health and resume his former social duties from which he was allowed temporary respite. The problem with this conceptual definition of behaviour displayed by a person following a psychiatric diagnosis lies in its presumption of recovery and resumption of activities and responsibilities formerly held while he was well. Psychiatric disorders, with chronic and recurrent courses of illness being essential features, render full and permanent recovery an unattainable or impossible goal[1]. There is no clear delineation of where "sick role" behaviour ends and where the "healthy role" resumes because even as the most florid and acute psychotic symptoms subside, the negative symptoms persist or set in. Furthermore, psychotic symptoms may erupt again during the period of the patient's recovery. While Parsons described an acceptance of the therapeutic regime (and the medical diagnosis) on the part of the patient as well as his commitment to leave this state of incapacitation, it has been shown that these obligations and rights (as described by Parsons) did not apply to psychosocial and mental disorders (Blackwell, 1967; Mechanic, 1975). Denzin and Spitzer (1966) found that the mental patient often denied his psychiatric status and resisted therapeutic intervention, due to his inability to understand or have insight into his problems (Greenfield, et. al. 1989). Parsons, did, however consider the emotional dimensions of illness and the sick role, and described the likelihood that the patient could be "open to, and peculiarly liable to, a whole series of ir- and non-rational beliefs and practices" (Parsons, 1951: 446, cited in Williams, 2005). It is thereby important to treat the mental patient's sick role as a protracted and even permanent state of role impairment.

From the observations I had gathered during my participant observations of caregivers' descriptions of their loved ones' behaviour during closed support group sessions, it is evident that patients displayed patterns of illness and recovery throughout

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[1] Erikson (1972) first contrasted the psychiatric sick role from the Parson's original concept of the medical sick role (1951). Kassebaum and Baumann's (1965) study of the chronically ill indicate that the nature of chronic mental illness makes role expectations that one should overcome illness and resume functioning in his former pre-illness capacity untenable. They also point to the fact that there is less need for a patient's exemption from performing his usual social roles when being ambulatory as opposed to being bed-ridden or physically incapacitated. Gallagher argues that mental patients with a strong "medical sick role orientation" (2002: 277) are more well-adjusted in hospitals because they exemplify the passivity and dependency required in a medical sick role, but fail to assimilate into the community after discharge because of the same dependency that had made them favourable inpatients.

the ex-patient phase, and these fluctuations were sometimes followed by repeated hospitalizations. Caregivers often believed that their loved ones had made full recovery from their mental illness only to discover to their surprise the return of disturbing symptoms. Uncertain of the cause of such behaviour patterns, some caregivers resumed their search for solutions. It is thus required of this study to clarify the "sick role" behaviour that schizophrenia patients manifest. I hold it to be protracted with an indeterminate period of recovery. Sick role behaviour commences upon the formal diagnosis of mental illness and includes the periods of relative normality between manifestations of acute, crisis states where psychotic symptoms erupt.

1.2 Theoretical Perspectives

Definitions of health and illness pervade the social life of humans in every society, where culture plays a central and integral part in the organization of health-related behaviour. Classical theorists considered culture central to the satisfaction of human needs, physical illness and beliefs about health. Max Weber defined "traditional action" as social action determined by "ingrained" habitual reactions to everyday life and stimuli (Weber, 1978:4). Malinowsky considered culture a functional response to man's "organic and basic needs", including the "relief or removal of sickness and pathological conditions" (Malinowsky, 1944:93). The view of culture as an integral body of ideas, rituals, beliefs and customs geared towards the eradication of or at least response to specific problems underscores the relevance of meaning systems inherent in any interactional setting. Social action, be it responses to social stimuli or actions undertaken in the search for help, is never far removed from the dictates of one's cultural dispositions.

Symbolic interaction concerns meanings which individuals give to their behaviour vis-à-vis others. It illustrates Cooley's original ideal of the self as capable of reflecting on its own behaviour (Cooley, 1902, 1909) and this concept of a *looking glass self* eventually contributed to George Herbert Mead's (1934) concept of the "self" which was built on Thomas and Thomas's (1928) earlier all-important principle of social-psychology: that whatever humans defined as real has real consequences (1928:572). This is how we arrived at the "definition of the situation", which links the perception of the extant environment and the way we act in it. As the individual internalizes the symbolic meanings and norms governing his behaviour, his perception of the world, his communication with others and his understanding of his external and interpersonal environment make up the process of socialization. This picture of social reality derives from Berger and Luckmann's (1966) classical statement about social reality being the transactional world in which everyday life is enacted, in which social roles are defined and performed, and in which people negotiate with each other in established status relationships under a system of cultural rules and norms.

This can take place in the family and in social groups found in education, occupation, rituals and through this, notes Berger and Luckmann, the individual fashions his own identity out of his inner (personal) and outer (social) beliefs, values and interests. This entails examination of subjective meanings attributed to events and emphasizes the role of perception in bringing about interaction and behaviour as "the actor selects, checks, suspends, regroups, and transforms the meanings in the light of the situation in which he is placed and the direction of his action" (Blumer 1969:5).

In fact, meanings are organised as "definitions of the situation", an integral concept in the social construction of illness, which includes the aetiology process of defining the situation (how symptoms are interpreted prior to seeking medical care) leading to the development and imposition of a medical diagnosis (Gerhardt 1989). Many researchers have since attempted to deal with the problem of definition, by exploring people's "lay explanations" of illness and how it determines modes of help-seeking and medical care.

Thus, the notion of meaning is pivotal to understanding coping behaviour because one directly precedes the other. One of the earliest studies of the meanings people had of mental disorder was that of Yarrow et al (1955) who studied how wives interpreted their husbands' odd behaviour prior to their first hospitalization. The wives' interpretations of their husbands' odd behaviour were found to shift but these were borne out of specific "systems of thinking" (1955: 21), and these are interpretive frames of reference that guide the observer's perception of behaviours as normal/abnormal, valued/devalued. They further show how certain patterns of contextual factors mediate the wives' interpretation of their husbands' behaviour in a mental-emotional-psychiatric framework. These are the protean nature of symptomatic behaviour, congruence of symptomatic behaviour with long-standing response patterns, communication styles between husband and wife, and the propensity of others in her network in defining his behaviour in a psychiatric manner or not. Responses marshaled by wives tended to be defensive, a result of normalizing their husbands' symptoms. Normalizing involves arriving at a satisfactory justification of the behaviour as not warranting cause for concern by seeing the behaviour as something that occurs in those who are not mentally ill. Another type of response is that of *attenuation* – seeing the behaviour as less serious than it is or redefining it as a momentary and hence temporary problem. Denial is the defense against the disturbing behaviour, and represents rejection of the psychiatric framework.

Zola's thesis on what leads people to eventually seek help has little to do with stress induced by the disease process, but stress triggered by a social-psychological process (1973). People don't seek help because their condition gets progressively severe and distressing, but because persons in their immediate environments notice and trigger medical help-seeking, or they perceive the condition as causing impairment to their ability to discharge their social functions or that it impedes social interaction. Zola's concept of a "temporalizing" or living with symptoms resonates with Clausen and Yarrow's description of how wives of schizophrenic men delay seeking psychiatric help. However, this is where the latter departs from Zola's explanation of the pathway to becoming a patient. The schizophrenic's pathway to hospitalization depends more on fortuitous circumstances than rational decision-making. The "trigger" in the case of the mentally ill is a situation that requires active intervention on the part of the caregiver or the police. The means of effecting the seeking of treatment may not necessarily be coercive, but these cases all illustrate the cumulative effect of symptoms that have exceeded the wives' tolerance threshold. The clergy, the police, general practitioners and members of the wives' social network play a role in getting the husbands into hospital, but in a manner that is haphazard and fraught with uncertainties about the course of action to take. As it were, disparate events of varying intensities piled up before hospitalization was effected, and this was shown to be a result of wives' difficulty at arriving at a "stable definition" of the nature of their husbands' problem (1955:32).

The stress-coping perspective which was derived from psychological research views distressing or threatening situations as stressors and a person who copes uses particular actions to reduce the magnitude of the problem. Folkman and Lazarus (1984) describe meaning in terms of "appraisal". Appraisal takes place when the individual considers whether the stressor is a harm or loss, a threat, challenge or whether it exacts a demand that is perceived as controllable or not. He then makes behavioural or cognitive attempts to manage the demands which are appraised as taxing. However, the concept of appraisal in the stress-coping framework does not adequately reflect the multiple facets of coping processes. Moos and Tsu (1977) point to the many aspects of stress that patients who suffer physical illness deal with, including pain and incapacitation, treatment environments and procedures while having to preserve their current emotional balance, self-image and relationships with their family and friends.

The cultural context is a pertinent factor which affects how people appraise a stressful situation, and if they perceive something to mean one thing or another. For example, Irving Zola (1966), one of the first to study how people from different ethnic groups reported pain, raised questions on the variability of differential illness experiences and explanations for different social groups. Zola's emphasis on the cultural context, how symptoms affected interpersonal behaviour and how these tendencies might be linked to cultural traits like expressiveness and dramatization underscore the need to explore belief systems, be they religious, cultural or steeped in one's own personal values. Boss, Kaplan and Gordon's (1994) study of Ojibwe women revealed that "stress" and burden were absent from their narratives of caring for a cognitively impaired elder. These women interpreted illness (Alzheimer's) not as a failure of functioning but as part of the circle of life, or "circular dependency", a belief that humans come into the world as children and will likely leave as children. They viewed caregiving as a valued part of life and objected to the use of the word "stress". Levine reported that beliefs in Confucianism and Taoism were associated with a higher tolerance for situations of high ambiguity and different interpretations of burden (1985). Value orientations found in people's religious, cultural or personal belief systems determine for them the *meaning* of stressors.

According to Cicourel (1973), individuals use interpretive processes to construct consensus during interactions. This has equal if not more weight on how roles unfold as do *a priori* structures. The major thrust of the phenomenological approach to family studies is that families have their own "private" understanding of the everyday world at large, in addition to the "public" dimension of the taken-for-granted everyday world. Subjective experiences must be understood by their intersubjective components (Berger and Kellner, 1964), and intersubjective meanings compose the commonly held and understood meanings in everyday life (Schutz, 1967).

To this end, the study of individual perception and beliefs is crucial to the development of effective solutions in response to mental illness in the family. From the framework of symbolic interaction, researchers have studied the problem of coping by using role theory (Merton, 1957; Parsons, 1951; Stryker and Statham, 1985) and contextual approaches (Boss, 2002). Social network theory (Suchman, 1965; Wellman, 1983; Lin, 2001) has augmented research on coping with illness, particular in the specific areas of medical utilization (Pescosolido, Gardner and Lubell, 1998) I will discuss and analyze these contributions to the issue of mental illness coping.

1.2.1 Role Theory

A role is defined as the normative expectations attached to a specific position in the social structure. Role theory conceives of interaction as a product of actors who adhere to the norms or expectations attached to their role. Mead (1934) describes the self as a developing product of social interaction which involves categorizing the person and ascribing meaning and expectations to the categories (such as gender) which leads to the process of role-taking, where individuals act, respond to others and evaluate themselves by considering reflexively the roles of others and of themselves. Interaction unfolds according to the role expectations and scripts that are anchored in the cultural milieu of the actors (Merton, 1957; Parsons, 1951; Stryker & Statham, 1985). A person may inhabit multiple social dimensions (work, home, community, friendship) and conform to different roles expectations, which may change over the life span.

The literature on role constructs in illness behaviour has shown that the appropriateness and inappropriateness of role response to the ill person can delay, prevent or promote recovery or at least the seeking of proper treatment. Inappropriate or maladjusted role expectations and attitudes can delay care-seeking, keep a person invalid or lead the ill person to attempt normal functioning before he is able. Findings show that when someone occupies an "impaired" role in a chronic and non-critical condition, he is denied certain rehabilitative social supports (Gordon, 1966) and may even be discouraged from seeking medical care. Simmons and Freeman (1968) found in their study that spouses had lower tolerance for deviant and disordered behaviour than parents. Therefore, the rate of re-hospitalisation was higher for husbands and wives. Parents had lower expectations of their child, who reverted to the dependent “child” role of son or daughter, which carries a relatively lower expectation of role performance.

An important limitation to role propositions is whether role expectations are clearly defined in every situation in order that the behavior expected of the other person with whom one interacts lies in congruity with one’s expectation of the perceived behaviour. The degree of consensus within a specific group of social actors depends on the congruence of role definitions and is fundamental to the continuity and organization of stable ongoing relations (Stryker, 1980). It is therefore important to explore caregivers’ beliefs about the obligations underlying their spouse, parent or sibling identities and their feelings about combining multiple roles.

For instance, gendered roles like motherhood is often associated with higher maternal facility, but this begs the question of whether mothers are better able to cope with caregiving responsibilities than single females or males. Suchman’s study of sex differences and illness behaviour concluded that “women are likely to be better informed about disease than men and to be less skeptical of medical care, but to be equally high in illness dependency” due to the possibility that “health and medical care are areas of greater salience for women as mothers responsible for the health of their families” (Mechanic, 1968: 260). Quah’s (1990) study of gender and preventive health practices tested sex-role expectations against several outcomes: whether this variable influenced (a) keeping of medicines at home; (b) practicing a protective activity against illness; (c) smoking abstention; (d) alcohol abstention and (e) regular exercise. She found that where women were more inclined to abstain from smoking and alcohol, gender role expectations of how women should behave was a stronger determinant than health campaigns and institutional influences. The protection of the family's physical well-being falls mainly in the woman's purview, as the mother's role as nurturer is socialised early and delineates what is socially expected of women's roles in terms of health behaviour (Quah, 1990: 63).

Role theory calls our attention to the structural embeddedness of particular social actors to the external context and the roles they play. But such a framework only emphasizes the dispositional likelihood to act, it doesn't show how actors would behave given a unique set of contingencies and actual resources with which to act.

1.2.2 The Contextual Approach

The major thrust of the phenomenological approach to family studies are that families have their own "private" understanding of the everyday world at large, in addition to the "public" dimension of the taken-for-granted everyday world. Subjective experiences must be understood by their intersubjective components (Berger and Kellner, 1964), and intersubjective meanings compose the commonly held and understood meanings in everyday life (Schutz, 1967). According to Cicourel (1973), individuals use interpretive processes to construct consensus during interactions. This has equal if not more weight on how roles unfold as do *a priori* structures. Contextual understanding of the family domain, therefore, refers to how actors explain or typify (Schutz, 1967) their experiences, which allow us to understand, in the manner of Weber's *verstehan*, the way meanings are constructed and explained to others.

Pauline Boss's process model of coping with family stress and crisis proposes that understanding the "internal and external contexts" of families determine how a family perceives troubling situations and react to them (2002: 28). Boss's contribution to the contextual approach to stress-coping in the "internal context" of her process model. It builds upon Pearlin and his colleagues' model (Pearlin et al, 1990) with two additional components: "ambiguous loss" and "boundary ambiguity". These two concepts are argued to be pivotal to the construction of symbolic meaning and subsequent appraisal (perception) of stressors. The "external context", which is beyond the control of individual cognitive efforts, refers to the individual or family's culture, history, economics, development and genetic makeup. She uses the term "perception" rather than appraisal, as the former embodies both cognitive and affective processes (Boss, 1988; 2002), which has been demonstrated in Clausen and Yarrow's study to affect the way people cope when a loved one becomes increasingly disordered.

The contextual approach emphasizes the importance of both perception and beliefs in responding to health problems as it acknowledges the existence of multiple contexts in the historical, cultural, economic and social overlap of a society that generate the particular systems of belief governing the actions of different personalities and dispositions. Individuals differ in their interpretation of family, social and cultural norms, their responses to crises or illness nevertheless reflect these social factors, as with their personalities and cognitive structures (Gochman, 1997). The provider of care, in the process of interacting with his or her family, social and community groups as well as other institutions (like work & healthcare organizations), also holds beliefs about the relationships among his or her roles that would influence perception and behaviour (Simon 1995).

For example, the cultural beliefs found in many Asian societies, juxtaposed against those of a Western one, demonstrate inimitable differences in people's approach to decision making. Personal orientations such as control and mastery are rooted in a Western belief in a "just" world (Lerner 1971; Lerner and Simmons 1966), the assumption that the world is just, and "good" people can control events that befall them. It is not very unlike the American ideal of rugged (or self) determination that characterises the notion that one is responsible for one's material success in life in spite of any and all social constraints. But such beliefs have led to the "blame the victim" idea that people in crisis deserve what they get. It veritably leads to the way coping strategies are taken (Boss 1988, 2002) and has unshakeable consequences for a family struggling to find logic in what they deem as an unjust and illogical befalling of tragedy upon them and their own. In Singapore, traditional beliefs about schizophrenia saw most people in the 1970s believing that spiritual "possession" caused mental illness. Tan and Long (1979) found that most of the diagnosed schizophrenics across all ethnic groups sought spiritual healers because the folk/religious concept of "god" is regarded as the only power that can counteract the "evil" or devilish forces believed to cause the mental illness. In a later study, it was found that over half of 153 consecutive first admissions to a psychiatric unit in Woodbridge Hospital had sought prior treatment at a spiritual healer (Tan, et. al. 1981). Their delusions were described by the authors as culturally specific to the local populace, because of the arguably pervasive belief that people can be inadvertently affected by *kongtow* (a black-magical substance placed in food or drink, or a spell cast on a personal article, object or place). They reported that the spirit medium was asked to help "treat" the patient who was believed to have been charmed by *kongtow*. However, this belief lies more often than not with the caregiver, who interprets the delusion as spirit possession (Tsoi, 1985), although 17 other patients had either auditory hallucinations of voices coming from gods and devils, or spirits who were "disturbing or who had possessed" them. Again, the reports from patients were vague and it is not clear if these interpretations belonged to the patient or the caregiver.

Geertsen et. al. (1975) found evidence of an association between group identity and beliefs and response to illness. They found that "group closeness and exclusivity" increased the likelihood of an individual seeking relief for a health problem "in a way that is consistent with his subcultural background" (1975:232). Value orientations found in people's religious, cultural or personal belief systems direct their perception of stressor events and how they should respond. The psychological concepts of self-mastery or personal control – believed to be vital resources in coping behaviour – are found in individuals or families with particular belief systems, which affect how they perceive themselves and their situation. For instance, fatalism, a belief that whatever happens is predetermined and beyond the control of the victim or afflicted person, is associated with certain groups that under utilize medical services and turn to folk or religious healing (King 1962) or staunchly refuse to take life saving precautions in the face of natural disasters (Kagitcibasi 1983; Frey 1963). Utilization of professional services has been found to be lower in Asian societies like Singapore with strong Confucian ideology systems (Kleinman 1986) where traditional and folk beliefs about mental illness still hold true (Kua, Chew and Ko, 1993).

It is important to recognize that a particular framework for responding to disordered bodies and mental states may survive and be continually revived from the vestiges of a particular historical cultural tradition. However, knowledge of and beliefs about the "traditional" is no longer easily separable or identifiable from that of the "modern", and I believe an insufficient analytical tool to explain the multifaceted dimensions of giving care to a schizophrenic family member.

Coping behaviour depends on the situation and the nature of the stressor, which of course varies in degrees to perception. Studies in this field included how individuals behaved and responded to a single role or relationship (Pearlin and Schooler 1978), singular events (Morris and Engle 1981), or recurring experiences (Boss et al 1979). Which sorts of people, under what conditions use certain coping strategies? Social networks and the idea of social support emerged from social psychiatry and social and cognitive psychology as important determinants of illness etiology, treatment and outcomes of health and illness (see Kadushin, 1969; Thoits, 1983; Freidson, 2001 for network theory).

1.2.3 Social Networks and Social Support

Social network theory and research have been central to promulgating ideas about how social networks affect the lives of people who confront, respond to and live with health problems. They approach human behaviour through the social interactions that occur between the self and the society, community or social system. Suchman (1965) argues that attitudes and information on seeking modern medical care are characterised by participation in society. Social group structures that influenced social relationships either determined a “cosmopolitan” or “parochial” outlook and attitude towards health seeking. This postulate led to modern network theory (Wellman 1983), which aims to understand human behaviour through social relationships or ties. Today, its basic premise is that individuals or organizations shape everyday lives and experiences through consultation, resource sharing, suggestion, support and even nagging (Pescosolido, Gardner and Lubell, 1998). Social networks have been implicated not only in the causes of illness and disease but also the recognition of problems as etiologically physical or mental, as well as help-seeking (knowledge, advice, access, barriers), involuntary treatment, care giving, adherence and outcomes (Pescosolido and Levy, 2002). Illness or stressors trigger a dynamic and social process of coping which places the individual in contact with various others to deal with a situation of uncertainty. Echoing Clausen and Yarrow’s (1955) original findings, Pescosolido and her colleagues discovered that families adapt to or normalize situations, delay on acting, seek opinions and advice about what to do, self-medicate or simply do nothing, adopting a wait-and-see approach (Pescosolido, Gardner and Lubell, 1998).

Nan Lin’s theory of social resources (2001) proposes that access to and use of better social resources leads to more successful instrumental action – the motivated intent of individuals to improve their positions (like job attainment) or problem solving. Resources are material and symbolic goods that can be used in such instrumental actions and are embedded in one’s social network and social ties. Social ties may be directly or indirectly related to the individual. They may be one’s friends, or an acquaintance from another social group.

Social resources have been studied in the analysis of the types of relationships that people have at their disposal (for instance, kin, spouse, confidant, neighbour), and the strength of such ties. This view of social relationships is critical because the strength of ties in caregivers' social network affect how accessible certain resources are to them. Also, certain ties may be activated or accessed only during certain times where highly specific types of aid or help may be needed. The content and function of social relationships have been often conceptualized and measured as "social support". Social support are a set of exchanges which provide the individual with material, instrumental and physical assistance, social contact and emotional sharing, as well as the sense that one is the continuing object of concern by others (Pilisuk and Parks, 1981). Support resources are believed to reside in the nuclear or extended kinship network, informal friendship or community sources (support groups; mutual aid help groups), and formal service providers. However, it remains unclear which types of support enable more efficacious coping for a caregiver, nor should we be too hasty to assume that the presence of networks presupposes the presence of social support.

In the case of kinship networks, large families or close-knit ties may result in adverse effects as these potential supportive resources may not always be activated or called upon in times of need. Pickett et. al. (1993) have documented in their research, evidence of low perceived support in African Americans as well as no clear relationship between support networks and perceptions of burden. The authors suggest the reasons being additional problems or strain brought on by the extended family and the reluctance to call on family or friends because of the fear that subjects will not be able to reciprocate the assistance.

The limits of social support from family networks can be observed in the management of illness. Mobilization of this kind is usually met during sicknesses of short duration, but chronic illness often requires a greater economic and psychological sacrifice than many kin are ready to provide (Moos, 1977). Granovetter (1973) studied how men used their social networks to find employment in the U.S. Compared to those with only strong ties, men who had both strong and weak social relationships were more advantaged. Infrequent ties that are not of central importance allow individuals access to other social networks and different sources of information. Stronger ties are often shared with people with similar knowledge with oneself, and thus similar or common access to opportunities. Hirsch has found that low density of family-friendship networks is related to more favourable coping with mid-life role transitions experienced by women re-entering student roles or becoming widowed (Hirsch, 1980). The women relied more on weaker ties like brief acquaintances that rendered them advice, explanation of issues and information sharing.

There is cause to regard close ties as having the *potential* for social support. The current generation still maintains ties with their kin, but it is my belief that with the advent of the nuclear family being the dominant family arrangement, these ties are less frequent and intimate than in previous generations. This doesn't necessarily imply that the nuclear family has become more isolated from society, but in fact it only means that family ties as a small and dense network with frequent interaction is no longer the main social form capable of protecting individuals from the confusing feedback and chaos of modern life (Pilisuk and Parks, 1983).

1.3 Conceptual Framework

To revisit the central questions that this study seeks to answer: How is schizophrenia recognized, interpreted and formally labeled a mental illness by the family member who later becomes a caregiver, and how do caregivers cope with the aftermath of diagnosis and hospital treatment?

Role theory and stress-coping theory contribute to the understanding of caregiving in recognizing social action as being conditioned by both contextual and individual influences. However, social network theory elucidates the dynamics of social interaction and how it affects the social organization of help-seeking and coping strategies. Social resources are an important construct that bridges the gap between personal and cultural beliefs and caregivers' utilization of and perceived accessibility to specialist care. A conceptual framework for explaining the process of responding and managing stressors arising from mental illness should capture as many of these components as possible. Figure 1 describes my conceptual model of caregiving.

1.3.1 Dependent Variable

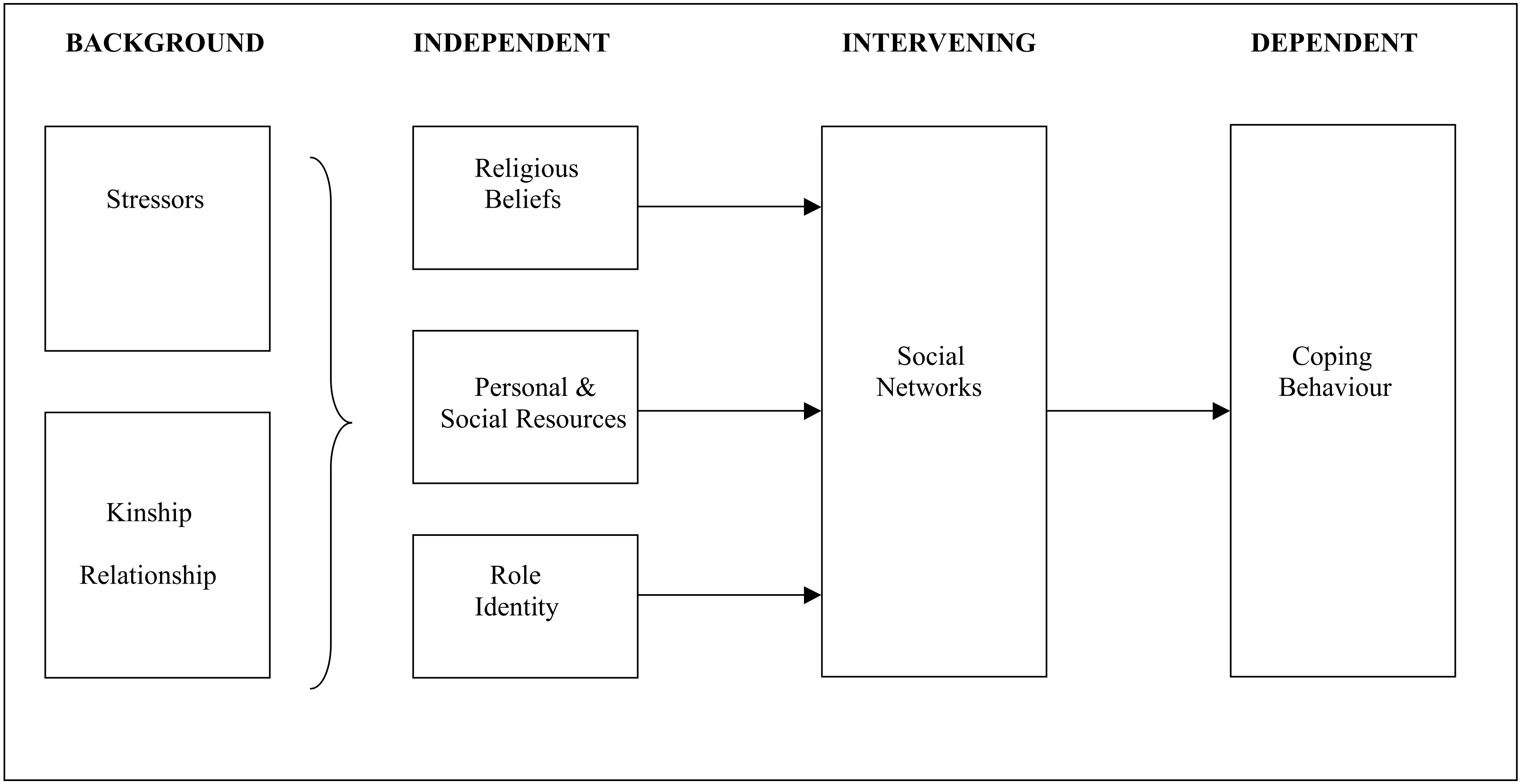
There are two dimensions of coping being studied. In the first, coping is called upon in situations where there is a specific stressor event with a noticeable time frame and where a series of responses and outcomes are played out. Defining a person's behaviour as being indicative of illness requires an assessment of the behaviour, assigning meaning to it and having a basis by which to compare expectations of normality concerning this type of behaviour.

The second dimension is of coping in everyday life where a constant negotiation takes place between caregiver, patient and environment, or the "management" of normality. Gerhardt defines it as achieving "maximum relative normality in the face of incapacitation or stigmatisation" (1989:139). In the wake of acute bouts of psychosis requiring hospitalization treatment, the analytic focus shifts from hospital to home or community, where most schizophrenics receive rehabilitative care. This includes maintaining the functional status of the patient like activities of daily living (being able to eat, dress, and maintain hygiene) and instrumental living (using the phone, going to the store, using public transportation, doing productive work or engaging in interests and hobbies) in addition to medication and psychosocial and therapeutic support.

Pearlin and associates (1990) identified three functions of coping that are specific to the lives of caregivers. Coping has the function of firstly managing the situation giving rise to stress; managing the meaning of the situation such that the threat is reduced; and managing of stress symptoms that result from the situation (1990: 590). However, the authors concede that coping efficacy cannot be judged solely by the content of the questions asked about coping. Their indicators only measure one component of the stress process, and a change in one of the components such as the context of stress may lead to a change in the others. There is a paucity of research evidencing exactly how meanings of situations are formed and managed and which domains produce stressors. There is evidence that certain gaps in knowledge from these perspectives could be filled with a more comprehensive approach to the problem. A qualitative case study approach is useful for explicating the exact parameters of coping as it needs to be understood in terms of the interactions that arise from caregiver-recipient, and the exact nature of stressors at which coping is directed.

A conceptual model depicting my research design is shown in Figure 3.1. This is simply a model of relationships between the variables that I have chosen to study in order to explain the phenomena of coping behavior. Any discussion of cause is inherently qualitative (Vogt, 2007:8) and the design of this research, which is the plan for collecting evidence, should not be confused with its measurement. My research design involves mainly in-depth interviews supplemented by participant observation. Therefore, the design of my research, exemplified by a model of conceptual relationships is compatible with the collection of both qualitative and quantitative data (Vogt, 2007).

Figure 1: Conceptual Framework



1.3.2 Background Variables

Stressors

A stressor is an unfolding event or series of happenings, which evoke reactions from observers and force them to define the situation. Such an event might be construed as distressful, it may exert a toll on the members of the family if it is prolonged (thereby causing "stress") and members may have to modify themselves or their social environment as a response. This is an occurrence that is of significant magnitude to provoke change because it disturbs the status quo (Boss 1988). Stressor events are not synonymous with stress, because the degree of discomfort (stress) depends largely on not just the magnitude of the event – contrast the recalcitrant refusal to observe daily personal hygiene with an attempted suicide bid that lands the recalcitrant in the mental hospital– but also on the family or significant other's perception of the event.

The type and nature of stressful events encountered by the caregiver influences how he or she manages illness. We know enough about the illness trajectory of a schizophrenic to envision a set of possible contingency situations where coping might be called upon. Severe mental illnesses that involve psychoses are usually episodic in nature. One might assume that its long duration points to a chronic sick role, but on the contrary, visible and obvious disturbances only flare up from time to time (depending on treatment adherence) and therefore schizophrenia's acute states must be distinguished from its chronic phase.

The duration and actual experience of caregiving may vary as well. In instances of mental illness, the episodic nature of the illness means that caregiving becomes significantly stressful or notably meaningful to the caregiver only during a relapse of the disorder (Becker and Morissey, 1988). The duration for which care is provided depends on other factors such as the severity of the situation that calls for the caregiver's attention and the commitment to treatment. For example, caregivers who do not insist on their charges' compliance with their psychiatrist's medication would often find themselves battling with a protracted series of relapses even when the condition isn't more severe than someone else with a similar prognosis. Experiences of burden thus depend on how each situation is perceived and which measures are taken to cope.

Kinship Relationship

Each caregiver in this study is related to the patient by either blood or marriage ties. I studied three caregiver-patient dyads: siblings, parent-and-child and spouses. Inherent in each relationship are different kinship bonds, filial obligations and role expectations that make up the varied patterns of interaction relevant to this study. The relationship dyad and marital or parental status of each individual plays an indispensable part in shaping his or her coping response in terms of the expectations a caregiver has of his kinship role and that of his loved one. The significance of role expectations will be discussed as an independent variable.

1.3.3 Independent Variables

Religious Beliefs

Parsons views culture as a product and determinant of human interaction and cultural traditions as being transmitted, learned and shared (1951). His concept follows Weber's earlier reasoning of social action, where he saw traditional action as "very often a matter of almost automatic reaction to habitual stimuli that guide behaviour in a course which has been repeatedly followed" (Weber 1978:4). Weber describes the stuff of everyday action as being the substance of attitudes, beliefs and customary practices, but emphasised the idea of "group affinity" as the substantive base of human groups such as ethnic and political entities. Subjective belief in a common identity – and not concrete social action – fuels group formation and the consciousness of certain shared attributes, as well as the juxtaposition of their apparent sameness against the diversity of other groups.

While culture can be regarded as an object, i.e. a corpus of shared knowledge, a body of routine practices or a set of values, it is also important to recognize culture as a dynamic process that includes the production and reification of knowledge, where practices are just as likely to be transformed and values reproduced. Obeyeskere describes this process of knowledge formation and transformation "whereby symbolic forms existing on the cultural level get created and recreated in the minds of the people" (1990:xix). In turn, culture may embody disciplinary and discursive forms of knowledge, functioning as institutional forms of power. Therefore, the learning and transmitting of cultural knowledge is not limited to ethnic or religious group membership.

Steinmetz (1988a) found that among families where an adult child undertook primary responsibility for the care of an elderly parent, the role of values transmission influenced the nature of the parent-child relationship. Attempting to explain elder abuse, Steinmetz studied caregiving dyads between the parent and adult child, and found emotional and physical violence to be passed on from one generation to the next, leading her to argue that the response of a caregiver usually reflected a similar behavioural disposition in the cared-for. In cases where caregivers tended to "ignore" the elderly parent, it was found that the elder usually displayed a form of antisocial behaviour not unlike the caregiver's "ignoring" treatment (Steinmetz, 1988b). Her observations pertain to parental and filial relationships, mainly in the explanation of patterns of care and abuse. Nevertheless, Steinmetz's research uncovers a pertinent aspect of familial relations, that *"the intergenerational transmission of values, attitudes and behaviours regarding the caregiving role throughout the life cycle is a critical link in explaining behaviour"* (1988a:176).

Singapore society, being of multiethnic composition and a plurality of groups characterised by religious, traditional, language, political and status affinity, is an intriguing case study where the transmission of social and secular political values intersect with those of the family and communitarian groups. Since all the subjects in this study belong to the same ethnic group (Chinese), I compare caregivers with different religious beliefs to explore possible cultural differences in caregiving.

Role Identity

Roles are expected ways of behaving that are attached to a position in society (Bates, 1956). Identities are meanings attributed to the self as object and a role identity is the meaning attributed to the social position one occupies (McCall and Simmons, 1966; Burke and Tully, 1977; Stryker, 1980; Thoits, 1983, 1986). Therefore, *parent* identity for instance, can be conceptualized as the feedback process in which the individual's perception of oneself as a father or mother is matched with an underlying standard of parent identity (Burke, 1991). A key interactionist proposition of role theory is that individuals' behaviour is guided by the roles they enact with role partners (Thoits, 1983, 1986). A caregiver's role identity is thereby a *family role* identity and consists of the meanings he or she attributes to being a parent, sibling, or spouse.

Since role identities provide normative expectations for appropriate role behaviour, they provide guidance for acting in specific situations (Thoits, 1983). A caregiver's self-conception (as the patient's father or sibling, or husband) determines his perception of the importance of his caregiving role and the responsibilities he assumes within that role. Simon (1997) found that the meanings people assigned to their family role identities were associated with the amount of mental and psychological distress they experienced. Horwitz and colleagues (1992) found that a hierarchy of obligations related to kinship roles determined which members of a nuclear family provided care to a mentally ill member and to what degree of involvement.

A caregiver enacts his role within a reciprocal role relationship with his or her loved one. It is likely that the flow of assistance – how much is given, whether it is one-sided or reciprocal – depends on the meanings that individuals attach to their role identities and their beliefs about the obligations underlying a spouse, parent or sibling role identities. This would explain the different approaches each caregiver chooses in coping with symptom recognition and managing problems associated with a loved ones' illness.

Personal and Social Resources

Nan Lin describes an available economic, political, labour or community "market place" from which resources can be drawn (2001:19). Individuals engage in interactions and networking to exchange and use social resources like information, help and other objects to produce a desired goal. Gore described resources as reflecting "reflect a latent dimension of coping because they define a potential for action, but not action itself (1985:266).

A frequently studied social resource that is pertinent to coping is social support. In the case of social support as a coping resource, we may consider it a social "fund" from which people draw when handling distress and difficulties. Thoits (2001) sums up social support as the functions performed for individuals by significant others, such as family members, friends and colleagues. The structural aspects of support (structural support) differ from functional aspects and structural support refers to the organization of people's ties to one another, particularly the number of relationships or social roles a person has, the frequency of contact with others, the density and multiplicity of relationships and so on. Studies of social support document the importance of access to and use of social relationships during crises in helping the individual adapt to psychosocial problems or to buffer the effects of stress (Levy 1983; Thoits 1982, 1983). Social support is meaningful in terms of the meeting of needs, and is viewed as part of the coping process. The conditions under which it is offered and received, as well as the timing of social support are questions that arise in this study. My emphasis is on how people recognize and manage their distressing circumstances after the onset of illness. I examine this by conceptualizing which social and cultural resources are available to them and how these are then marshaled in response to illness.

Personal resources embedded in experiences prior to taking on a caregiving role have a positive impact on the experience. These may be instrumental resources like education, or personality attributes like higher levels of emotional well-being (Brown and

Harris, 1978). Townsend et al's (1989) study found that coping improved with the age of the caregiver, likely due to such personal resources. Moen et al (1995) found evidence that previous psychological well-being and social integration (religiosity, social support and multiple role involvements) predicted subsequent well-being during caregiving. Having non-family roles such as volunteerism and paid work also moderated stress from caregiving. If previous experiences are associated with the perception of how much difficulty one is currently experiencing, one can imagine that certain types of roles offer resources that may be instrumentally helpful to the caregiver. Hence, *age and role changes* are part of the broad base of personal and social resources that a person may bring to the caregiver role.

1.3.5 Intervening Variable

<u>Social Networks</u>

In Lin's discussion of resources embedded in social relations, he talks about a critical component of access to social networks. "Only when he or she is aware of their presence, and of what resources they possess or can access can the individual capitalize such ties and resources" (Lin, 2001:25). In most schizophrenia cases, as well as other forms of severe mental illnesses, refusal to participate in mental health treatment itself is a common occurrence, and "the primary determinant of the failure to seek care is a lack of awareness or knowledge of illness and symptomatology" (Hawley 1997:255). Oftentimes, people rely on lay knowledge to make sense of the disturbing signs, or rely on other close network members' opinions, which often tend not to concur with their own lay understanding. They would not normally have the necessary education or medical knowledge (human capital) to recognize the illness, and could very well stay outside the realm of formal mental health networks until they gain access to somebody with the requisite knowledge to identify the problem as psychiatric in nature. On the other hand, lay advisors may also suggest non psychiatric treatment strategies such as spiritual healing. For these reasons, I have chosen to study social networks as a separate variable, even though it is a subset of social and personal resources. I posit that social networks are an integral mediator of how different kinds of social resources are used in response to a crisis.

The concept of networks has been used extensively in the study of social relationships in health-related research (Tausig, Fisher and Tessler 1992; Cresswell et al 1987; Froland et al 1979; Cook 1988). Social relationships are mapped by using three concepts in social network theory: structure, content and function (Pescosolido 2001). The structure of a network is the characteristics that describe the form of the network (size, strength of ties, density, scope) or how social ties in it are linked. The network content are characteristics of the social ties that describe the substance of the network, such as attitudes and beliefs. Lastly, the functions of the network describe what the social ties do, for instance, whether they provide emotional or social support, instrumental aid or regulation and monitoring. Studying caregivers' networks and their function will elucidate both the potentialities and actual social resources available to them. I posit this variable as an intervening one.

1.3.6 Controlled Variable

The variable of ethnicity is kept constant. Ethnicity has been more of a confounding than contributing factor in studies of support provision and family obligations. Pruchno et al (1997) suggested that black families have a "mutual aid system" that values reciprocity and social responsibility which explains the lower caregiving burden and higher satisfaction scores found in their sample. Yet research on African-American and white caregivers show an inverse relationship where black caregivers report little or insufficient support. Biegel et al (1991) report that when socioeconomic status (SES) is controlled, ethnicity does not affect burden. SES more than ethnicity determines different patterns of family caregiving while evidence of a support system implies only the *perception* on the part of caregivers that they receive help. Therefore, all the cases in this study are of Chinese caregivers.

The next three chapters consist of findings from participant observations within closed support groups as well as in-depth interviews conducted with twelve caregivers. A discussion of methodological issues as well as the semi-structured interview questionnaire is appended in Appendix III.

CHAPTER TWO

THE SEARCH FOR CARE: INSANITY AND WHAT IT MEANS

Before I present the themes of this chapter, I will revisit the central question of this thesis: how does culture and society shape and influence the process and practices surrounding the care of a schizophrenic? In my conceptual framework presented in Chapter One, I proposed to approach this research problem by studying the social and cultural resources of twelve caregivers. The most salient issues in this chapter are: the problem of delay in help-seeking and treatment; the search for medical and psychosocial aid as well as the perceptions caregivers have of the cause, treatment and recovery from a severe mental illness. From my point of view, these twelve cases reveal that social resources, cultural knowledge and role identity serve as the cultural toolkit (Swidler, 2001) for meaning-making and choices of action. They led to the use of certain illness meanings for coping.

The first section deals with the problem of recognizing signs of illness and help-seeking actions that follow in the search for appropriate care or solutions to what is perceived by respondents as signs of abnormality or disorder. I will examine the actions taken in response to these interpretations, showing how the multiplicity of health-seeking options and encounters between care-givers and other social actors forge various patterns of coping responses. Cultural meanings of sanity and insanity influence the decision to seek care and the type of care selected, and I will show how the caregivers' coping behaviour (which include decisions *not* to act, or temporalize) is explained by their different illness meanings. In the second section I discuss the issue of temporalization and forward an explanation of delay in seeking help for a loved one in spite of observable signs of insanity.

2.1 Meanings of Insanity and Meaningful (In) Action

> Let me begin by asking you about your (kinship relation)'s illness. How did you discover that he had schizophrenia? [Interviewer]

This question evinces the first important theme of this chapter: how signs of mental disorder were first interpreted and appraised. The starting point for a particular incident, specific period, or a turn of events that epitomized the beginning of something "abnormal" was, for each caregiver, different. All the care-givers have had no knowledge or personal experience of the meaning of schizophrenia, and perceptions of behaviorial aberrations tended to undergo a series of changes, irrespective of the length of time elapsing between the first awareness of concern and psychiatric treatment and/or hospitalization. The narratives from the caregivers in this study also contain their confusion and multiple meanings they assigned to their loved ones' behaviors as they unfolded. Three kinds of caregiving responses were discerned from the various ways the caregivers coped with disturbing behaviour – these are what I term illness meanings or definitions. In some cases, a caregiver would use one illness meaning exclusively, while in others, different meanings were used simultaneously to make sense of the situation.

2.1.1 Spiritual-Religious Meaning of Illness

The interpretation of behaviour symptomatic of psychosis as spiritual disturbance rather than a mental/psychiatric manifestation offered caregivers strategies for meaning-making and response. However, in the cases of obtaining aid from traditional healers other than the biomedical practitioners, caregivers' interpretation of what was befalling their loved ones was not bounded solely by a clear definition of illness. Spiritual or religious explanations were always paired with or supplemented the psychiatric interpretation. There were three cases in which this happened: Melvin and Anna used a spiritual-religious coping strategy after they had sought help from psychiatrists. Rina used spiritual/religious healing methods before her son was formally diagnosed and treated for schizophrenia. I will present Rina's case to illustrate how the spiritual-religious illness meaning was employed in tandem with a psychiatric one in their search for care. Melvin and Anna's strategies will be discussed in the next chapter on coping *after* a medical diagnosis is made.

Rina, 46, Zihai's mother[2]

In January 2004, Rina's fifteen year old son Zihai began to display very bizarre behaviour. He would talk incessantly to "people" at his window, convinced that people at the market below his block of flats were making fun of him [1][3]. Rina immediately identified her son's behaviour as signs of mental abnormality, and believed that the problem could be a spiritual one, that Zihai had been a victim of "black magic". Within a few days, his behaviour had become worrying enough for Rina to take action, seeking advice from her family and friends. Her beliefs were supported by friends with interpretations of insanity. As a result of well-meaning advice from friends, she went to two shamans, also known as "tang ki" who performed healing rituals [2]. While Rina sought the services of various traditional healers, she was coterminously using a medical

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[2] See Appendix I for a list of information on the study subjects.

[3] See Appendix II for subjects' quotations.

interpretation as another problem-solving strategy, as the spiritual healing was not improving Zihai's symptoms. Her husband's colleague had a son who had displayed similar behaviour as Zihai's, and advised Rina's husband to go to a psychiatrist at once [3]. Rina and her husband took Zihai to the Accident and Emergency (A&E) room at the Woodbridge Hospital. They were told that "it was schizophrenia", Zihai was given Risperdal (an antipsychotic drug) and referred to the Child Guidance Clinic (state psychiatric clinic catering to adolescents). When I asked her which explanation of her son's illness she was more convinced by at that time, she said she was equally convinced by both interpretations as they offered her two "strategies" for seeking help.

Anna, 50, Sean's mother

In 2003, at the age of 23, Sean had his first day at work as an auditor. When he got home that evening, he asked his mother Anna if she could hear "voices". Anna could only hear the sounds of children from the nearby playground, and became even more mystified when Sean told her he had been followed on his way to work. He started throwing things away, saying that his brother's T-shirts were "evil". On the second day, Sean became very quiet, and ate very little, his face "changed to become very solemn". That night, Anna woke at 2am, Sean had called the police complaining of "peeping toms" and a neighbour who was spying on him. The police suspected a mental problem, and advised Anna to take Sean "for treatment". Anna was panicky, and feeling afraid for Sean, decided to take him to a polyclinic. Sean refused to go, and Anna had to get her husband to convince Sean to go to the doctor "for his mother". At the polyclinic, sensing that his parents had deceived him, Sean ranted that "[he] was not sick, [he was] not crazy". The doctor had a look at Sean and after hearing what had happened from Anna, diagnosed Sean as having schizophrenia. He wrote Sean a referral for an appointment with a psychiatrist at the Institute of Mental Health. They had to wait almost two months before Sean could see the psychiatrist. Unfortunately, Sean's condition worsened shortly after his polyclinic visit. On New Year's Day, Sean started to pray loudly and incoherently in the living room. He sang until his throat "became sore" and wore a "stoned" expression on his face. Anna recalled, "Suddenly he took the Bible, put in the bag with a bottle of water, he was very strong…he just left. My husband tried but couldn't follow him." Fearful and panicky, Anna called her sister for help, and was advised to perform a folk-spiritual ritual [4].

Anna's sister believed that the "spirit" of the psychotic was perceived as having left the body, hence, the ritual performance using an article of clothing could "summon" it back, thereby restoring normality. Sean had reached such a heightened state of psychosis (where his behaviour had become extremely disturbing, disorganized and incoherent) that she used a coping strategy that was suggested to her because she was responding to a particularly urgent situation. Later, Anna called another friend from church, who was a psychologist. He advised her to send for an ambulance and take Sean to the hospital immediately. When Sean finally called from his grandfather's house that evening, he refused to go home because the house was "evil". Sean would not budge and nobody was strong enough to make him. Anna called for a private ambulance, and at 1am the next day, Sean was coaxed into the ambulance and taken to Woodbridge Hospital.

The spiritual-religious meaning of illness consists of blend of Chinese folk beliefs with the more dominant religious systems of Buddhism, Taoism and Christianity. Anna and Rina's meanings of illness, to a smaller or larger extent, offered a cultural practice of rituals and beliefs which provided them a pragmatic way of coping with their loved ones' problems. Although Anna was cognizant of the possibility that Sean had a mental problem, she resorted to using the only available strategy at the time of his crisis, until an acquaintance from her church suggested an alternative coping strategy: to call for a private ambulance.

Among the Chinese Buddhists in Singapore, two distinct categories emerge: the first group practices the teachings of the Buddha, they follow the canonical traditions of the Theraveda or Mahayana schools. Most Singaporean Buddhists and Taoists for that matter fall under the second group which has no canonical references: the Chinese syncretic religion (Wee 1976) which is a combination of Buddhist precepts with an indigenized tradition involving animism, shamanism and ritual experts to produce a system of supernatural beliefs and practices. The element of spiritualism is highly present in this system of folk belief, as the Chinese worship and pray to a number of other *shens* (deities or gods) besides the image of the Buddha. Shamanism, or spirit-mediumship predominates as a healing practice within this system of belief. It is believed that a person can be possessed or disturbed by malevolent spirits or "gui" (common Mandarin term for "ghosts") and other supernatural phenomena, and that he can be exorcised by a *tang-ki* (contemporary name used in Taiwan and Singapore for shaman or witch doctor) through a ritual-healing session. Mental illness has been associated with beliefs about demon-possession (Tseng 1973) and an earlier Singaporean study revealed that all but one Chinese sufferer of schizophrenia had visited a spirit medium before arriving at the psychiatric hospital (Tan, Chee and Long, 1981).

In 95 per cent of the world's cultures, trance and possession states are routine forms of everyday experience (Bourguinon, 1976) while theories of natural (medical-scientific) and supernatural (and moral) causation are found in all societies in the world (Murdoch et. al, 1978). In Chinese populations, these states are more common among rural populations who maintain a strong orientation to traditional folk religion, but Davis (1992) demonstrates that in urban Taiwan, lower middle-class and well-educated Chinese alike participate in religious ritual activities in which supplicants and healers utilize possession by gods, ghosts, or ancestors as problem-solving or healing methods. The traditional-modern dichotomy obscures the pragmatic element in help-seeking choices. Folk and religious healing practices are depicted as inordinately important in culture-bound syndromes especially implicating the lower educated, or those who retain their "culturally-constituted belief" (Tan, Chee and Long 1981[4]) in spite of socialization within the host culture or against Westernizing influences, and assumes incompatibility with modern psychiatry and scientific rationality.

"Pragmatic acculturation" offers another view of utilization, the idea based on the borrowing of different health resources from a plurality of healing systems in order to satisfy specific needs (Quah, 1989:6). Quah's observations of Singapore (1977; 1989)

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[4] Tan, Chee and Long (1981) argued that the Chinese in Southeast Asia, being descendants of peasant migrants from China, have retained a "sequestration" of folk beliefs (1981: 379) held by their ancestors. These beliefs, particularly regarding psychiatric symptoms, tended to be mirrored in the beliefs of the indigenous populations as well, reinforcing the tendency to perceive schizophrenia symptomatology within a transcultural "spirit-possession" framework. Culture-bound syndromes such as spirit-possession and amok (a loose agglomeration of deviance and psychopathology, usually amongst those who have been violent and homicidal) are influenced by the cultural beliefs and norms and also reinforced by the social response of others in the community. Tan (1981) avers that the values and norms of that society determine how symptoms of culture-bound syndromes are expressed, perceived and summarily labeled by the community. In turn, knowledge of these syndromes and of the cultural belief system they are based upon is transmitted, reaffirmed and renewed by the purveyors of the treatments considered efficacious for the relief of these syndromes and symptoms.

concurs with some medical anthropologists (Kramer and Thomas 1982; Bhopal 1986; Anderson 1987) who discovered that people were able to harness the diversity of healing resources for a myriad of health needs with little conflict from the “traditional-modern” split. The co-existence of plural medical paradigms in Singapore, as well as the complimentary borrowing from other cultures apparent in Singaporeans’ utilization underscores the element of pragmatism and practicality in making treatment decisions.

2.1.2 Normative Meanings of Illness

Normative interpretations evidence how caregivers cognitively recognized abnormality as a deviation from a cultural pattern of normatively constituted social behaviours and interactions. The result of interpreting disturbing behaviour normatively delayed the seeking help for the “deviant”, because insanity was perceived as something culturally and socially acceptable and therefore tolerated. The following case excerpts illustrate normalizing and temporalizing strategies for coping with disturbing behaviour. Meanings of insanity took on two types of normative interpretations that led to two types of accommodation practices: defining odd behaviour as normal within the social or individual context (normalizing) and tolerating behaviour which was perceived by family members as abnormal.

The interpretation of bizarre behaviour as a by-product of something else, usually a character trait associated with the person exhibiting the abnormality, led to the caregiver accepting the behaviour as rational or justifiable under those circumstances. Inexplicable or difficult behaviour was defined as “normal”, an interpretation which didn’t cause the caregiver enough discomfort to intervene.

Melvin, 49, Sharon's father

Melvin's daughter, Sharon started to see people that were not there at the age of nine. What was real enough for her to report the "sightings" to her parents however left them perplexed [5]. To her parents, Sharon's strange remarks of seeing "people" who were invisible to other observers were attributed to her imagination, caused by her penchant for horror movies. While her hallucinations were "abnormal" in terms of what is empirically verifiable and thereby ontologically real to her parents, an overactive imagination was quite acceptable and hence "normal" for a nine-year-old. In this regard, her parents could normalize her odd behaviour by selecting an interpretation which restored the "normal" order of interactions.

Ten years later, at age sixteen, Sharon spent a few months at a fast food outlet on a work attachment for her vocational studies. She began to complain about stress from work and a demanding boss who often reprimanded her. She quit shortly after, albeit with some objections from Melvin, who told me he didn't like the idea of her "doing nothing". A year later, Melvin and his wife saw a noticeable change in Sharon. She had become very isolated, started talking to her stuffed toys and there were cuts and bruises on her arms. They suspected Sharon had been cutting her hands, and things got worse when she started compulsively going to the toilet late into the night. This was followed by what Melvin perceived as a suicide attempt [6]. Melvin's wife related the troubling incident to her brother; he spoke to a psychiatrist – a fellow colleague who advised psychiatric treatment. The conception of his daughter's problem as a psychiatric one eluded him until symptoms had intensified to a point where he had no choice but redefine them as mental/medical.

Wei Rong, 52, Maggie's husband

Wei Rong and Maggie married in 1981 and had two sons who are now teenagers. For most of their married life until 1994, Wei Rong's wife disappeared periodically from the family home after having an "outburst" about what she believed was her husband's infidelity. She even filed for legal separation in 1993, convinced that if she did not leave her marriage, "something tragic would befall the family". Wei Rong was "at a loss to do anything". Maggie was finally taken to the mental hospital by police when she caused a scene at a public place [7].

Wei Rong had attributed his wife's disappearance to her habitual behaviour that had come to be "expected" and "not unusual". Wei Rong's responses to disturbing signs prior to this incident in 1994 retrospectively contain a normalizing tendency in the same vein as Melvin's attributions. His wife Maggie's leaving home, her paranoia that he was having affairs, allowed Wei Rong to interpret early signs as manifestations of her difficult personality. In fact, Maggie's paranoia and erratic actions were normalized under Wei Rong's evaluation of Maggie being "bad tempered" and not being able to communicate or interact like "normal" people [8]. He believed at the time that Maggie, having grown up in Taiwan and not having her own family in Singapore, might simply have had trouble adjusting to life in Singapore. "Even though I got the IDD for her so she could phone her parents in Taiwan, she didn't use it! I just thought she was very stubborn and introverted at the time," Wei Rong said. Despite the recognition that there was something not quite normal about Maggie, Wei Rong defined illness signs as a problem arising from her character rather than her mental state, seeing that she did not communicate as a "normal" person would. Hence, Wei Rong perceived Maggie's behaviour as justifiable within the framework of a troubled and difficult personality type. These signs nevertheless troubled Wei Rong, since they did impinge on his children and on the marriage.

In the next two cases, these caregivers and their families perceived their loved ones' deviant behaviour as signs of mental instability. Like the families that normalized behavioural aberrations for long periods of time, they too did so for many years. For Janine's and James' families, the awareness that something was not normal about their loved one was evident, but not normalized. Family members tended not to speak openly about a "problem" with the deviant member, but there was evidence that the behaviour had been stressful for the family. In fact the symptom manifestations in these two cases seemed to be more severe and were interpreted as signs of insanity by the caregivers.

Janine, 36, Mrs Lin's daughter

The earliest recollection of when "it all began" for Mrs Lin, Janine's mother, was in 1977 when Janine was just six or seven years old. Her mother began having "unfocused conversations" with her and her six siblings, getting very "agitated and excited" whenever she heard the siren of a passing ambulance. Janine described her mother's behaviour then as not being very serious, and it would be ten more years before things got worse. In 1982, Mrs Lin began to show signs of physical deterioration. This had come in the wake of Janine's father's financial troubles, his failing business, mounting debts and her parents' incessant and violent fights. Janine's father eventually fled the family home and the pursuit of loansharks who were harassing the family for the money he owed them; her elder sister ran away and Mrs Lin's parents passed away shortly after. Relatives tried to help by offering her mother Chinese herbs when she began losing weight and “bleeding nonstop [menstrually]”, which went on unabated for years. Janine was thirteen, and knew that something was wrong. She explained her mother’s “breakdown” as a reaction to her elder sister running away, her grandparents’ deaths and her father’s absence [9].

It was in 1992 when Mrs Lin’s weight loss had become so dramatic that Janine and her siblings became concerned. Her mother eventually saw a biomedical practitioner, who found nothing wrong with her. The only diagnosis the doctor could offer was that “she just lost a lot of weight” and no medication was prescribed. Almost three years later, Janine’s mother’s weight had dropped to a paltry 38 kg and on top of that she was “getting anxious about some glass in her sole”. Her mother presented her problems to the doctor again, and again the GP found nothing physically wrong. It was at her adamant insistence that there was glass in her foot that she was given a letter of referral for psychiatric examination at a community polyclinic. This time, Janine accompanied her mother to the psychiatrist, and the doctor confirmed it was mental illness. Janine gave consent to have her mother taken to the mental hospital, against her mother’s will. Unfortunately, Janine’s relatives as well as her siblings chastised her for doing that and after three days, she got her mother discharged against an attending doctor’s advice [10]. Janine confessed that the reason she had discharged her mother from hospital and was because she believed that it would do her more harm than good. She believed that her mother’s condition would worsen after hearing of her friend’s similar experience with the latter’s father. Her relatives berated her for what she believed was the “shame” of taking her own mother to the mental hospital [11]. After Janine took her mother home, things did not improve. One of her sisters tried to slip some of the prescribed medication into her mother's food, but being "very sensitive", Mrs Lin refused the food. Over the next ten years, her disturbing behaviour progressively intensified, and her children could only watch helplessly, in Janine's words, they "tolerated it for another ten years" [12].

In spite of the family members' belief that some kind of insanity was at work, and that Mrs Lin had been treated for psychiatric illness, Janine delayed getting treatment for her mother a second time. In fact there is evidence from Janine's narrative that the family denied that her mother had a mental illness at all [13].

Janine's mother's problem was perceived within a normative view of what she saw as a "violent", dysfunctional family. Her mother's abnormality was in fact perceived as a function of the entire family's abnormality, something that the young Janine felt very strongly about, as she spoke of not getting "acceptance" from her relatives and friends for the way her mother was. It was only after her mother's condition progressively intensified in severity over the next fifteen years that Janine came to believe that her mother was indeed suffering from a mental illness. Another source of tension lies in the social reaction from relatives and close friends. Stigma, (Goffman, 1964) as a negative label arising from being hospitalized for a mental disorder, has been a strong influencing factor to whether the mentally ill receive and comply with treatment (Link & Phelan, 2001; Gallo, 1999; Wahl, 1999; Link 1982; Farina and Felner, 1973). Proponents of the "societal reaction" hypothesis[5] or social labeling (Lemert, 1946; Becker 1964) describe how adverse societal reaction to the stigmatizing label of mental disorder creates a

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[5] Phillips (1963) associated the likelihood of patients seeking psychiatric help with the degree of perceived social rejection on their part. Patients reported feeling more ostracism as they sought more professional help sources.

deviant role which the labeled occupies. By this logic, the very act of hospitalizing a family member for mental illness entails the potentiality of incurring a spoiled identity.

James, 36, Henry's brother

Henry is eight years older than James. James has been his primary caregiver for the past sixteen years and like Janine, the one who initiated the search for care. In 1989, James noticed that his brother was behaving very strangely, that Henry was not "normal". He spoke to himself, or at least to persons invisible to his family members, and would brandish a meat cleaver, hacking at the walls. For the next five years, Henry showed no signs of improvement, he didn't work and was "very dirty" because he did not bathe. During this time, although James and his siblings were disturbed by Henry's behaviour, nobody did anything, and the family coped by avoiding Henry at all costs [14].

When James graduated from university, he went in search of answers that would explain Henry's troubling behaviour. "Why was my brother acting like that?" he asked an old friend after a soccer game one day. The friend listened to James' description of Henry's behaviour, and suggested that it could be mental illness and that Henry should be given medication. James acted on this, as another acquaintance from his church had also suggested that Henry's problem could be psychiatric. He attended a seminar at the Institute of Mental Health, where he became more certain after that of the nature of Henry's problem. It was at this point that the normative framework that James had always used changed to a biomedical one, and he turned to using an active coping strategy. The problem then for James was how to get Henry into a hospital, as he "would not do anything, or go anywhere, much less a mental hospital. The problem was solved with the use of a little deceit. James talked Henry into getting into a cab with him to go meet some of James' friends for a meal. Henry agreed, and James got them to the mental hospital. Unfortunately, Henry's suspicions got the better of him, and managed to escape before a psychiatrist could examine him. James managed to convince the psychiatrist at the hospital to let him have medication for Henry even though he had not personally examined him [15].

For the next two years, James successfully medicated Henry without his knowledge, and Henry recovered slowly and surely. After five years of tolerating an obviously disturbed family member at home, James decided that "it was time to do something about the problem". He felt a tremendous amount of guilt at having to resort to trickery, he said, and was mentally apologizing to his brother on their clandestine trip to the hospital.

For Janine, the resistance to both the psychiatric diagnosis and treatment appears to be connected to social stigma and avoidance of it, culminating in a denial of mental illness and the continued use of a normative illness meaning that explained her mother's insanity in terms of deviance rather than illness. It took fifteen more years and her own brother's mental breakdown before Janine made the decision to get treatment for her mother. The problem of delay in Janine and James' cases were similar in that they were both siblings of the afflicted individual. The third sibling caregiver, Grace, had taken her brother, Jeffrey, to a psychiatrist not long after he showed signs of mood and behavioural changes. Grace's brother's condition had worsened much more swiftly from the time his family members became aware of the signs, and unlike Mrs Lin and Henry, he had assaulted a relative and was violently aggressive at home and in public. In Janine and James' cases, the reason for tolerating and accommodating their loved ones' bizarre and distressing behaviour can be explained by the use of their normative interpretations of their loved ones' insanity. However, such a long period of delay and inaction even in the face of severe debilitation in their loved ones' functioning capacities has to be explained. Comparatively, Wei Rong had not sought any help for his wife either, in more than ten years. However, Wei Rong had not perceived Maggie's problem as a mental one in any way, rather, he had found an illness meaning that normalized her difficult behaviour.

2.1.3 Medical Meanings of Illness

During an acute episode or what care-givers informally call the "crisis" stage, patients would display outward signs of disturbance in their mannerisms and interactions with others. Their behaviour would become extremely erratic or bizarre and usually irrational, though extremely violent behaviour was not a characteristic feature. Such episodes would typically take place within the home, and unlike other studies that focus on the working class, the visibility of the symptoms are restricted to the home or workplace where the patients spent most of their time. Only in one case did public transgressions of norms or displays of deviance result in police intervention resulting in forced admission to a mental hospital; instead family members were the ones who took action, often by coercive means although many eschewed psychiatric hospitalization, preferring to delay action until they received an obvious cue that something was seriously wrong with their loved ones. These were *mediators* (police, general medical practitioners, psychiatrists and other healthcare professionals), what Goffman described as the "agents or agencies to which the prepatient is referred and through which he is relayed and processed on his way to the hospital" (1959: 126). *Complainants* – the person who retrospectively appears to have started the process towards hospitalization – were also contingent to the caregiver's adoption of a medical perspective or meaning of illness, contrary to Goffman's assertion that mediators who were specialists in handling problems of this nature were more likely to be "psychiatrically oriented than the lay public" (1959: 126). In two cases (Janine's brother and Siew Min's son), a supervisor at work called the caregiver and request that they take their loved one for treatment. This occurred after the loved one had began to show signs of disturbance, and only confirmed what the caregiver already suspected – that the problem was a mental one. Police who were summoned by either a next-of-kin or the prepatient himself advised psychiatric treatment in two other cases (Ronald's wife, Anna's son). In four cases, lay persons (relatives and friends of the caregiver or his family) were responsible for giving advice on seeking psychiatric help (Melvin's daughter, James' brother, Grace's brother and Rina's son). Complainants, mediators and lay advisors are illustrative of the *sequence* of agents (with or without professional expertise or the legal mandate to sanction commitment) involved in the eventual outcome of hospitalization and diagnosis.

For Janine, who was introduced in the previous section as a caregiver to her mother, a complainant – Sam's boss – triggered the first decision on her part to seek help for her younger brother. Janine's younger brother, Sam, had been displaying changes in his routine weeks before he had a crisis at work. It was 2001, in the weeks leading up to Janine's older brother's wedding, that Sam started coming home in the wee hours of the morning. He had asked his boss for overtime every day so he wouldn't have to go home. Janine also discovered that Sam would go jogging for hours at night, refusing to go home. Janine got a phone call from Sam's boss the day his strange behaviour exacerbated to a full-blown crisis at the office [16]. Janine had noticed the changes in her brother before his crisis at the office, and in fact, she had suspected that Sam had checked himself into a private hospital for treatment some time ago. She discovered quite by chance that Sam had previously admitted himself to a private mental hospital and a check with the psychiatrist there confirmed that he had been diagnosed with a mental illness [17].

Ronald, Dolores' husband

Ronald's case illustrates how a fortuitous encounter with a mediator – a policeman who happened to be Ronald's old friend – changed his normative interpretation of his wife's inexplicable and difficult behaviour to a psychiatric one.

Ronald and Dolores had been married almost two years when Dolores started showing changes in her mood and behaviour. Ronald was one of the two husbands who knew about their wives' mental illness when they married. Even though Ronald was cognizant of Dolores' history of mental disorder, her family had been tight-lipped about it and all Ronald knew was that his wife had been a patient at the Woodbridge Hospital (the only state mental health facility) when she was sixteen. Two years after marriage and shortly after Dolores was laid off from her job, Ronald started noticing his wife's transformation from a "warm and bubbly girl who loved my mother" to someone who was "very argumentative, and easily irritated". Dolores would have crying spells and ever so often, Ronald would come home to find his wife "all dolled up", asking him coyly if he found her attractive. The odd behaviour worsened when Dolores became openly antagonistic and aggressive towards her mother-in-law and the other members of the family. Her brother-in-law phoned for the police, who advised mental hospitalization [18].

Dolores was perceived as threatening to her relatives at home, and such situations are typically contingent upon a sudden, acute episode where the patient becomes severely agitated and displays bellicosity and aggression in speech and behaviour. Observers interpreted the behaviour using a normative framework, where the subject was perceived as offensive, unstable and a threat to those around her. Ronald did not suspect that Dolores' problem was a manifestation of mental illness and did not take any help-seeking action, choosing to temporalize and accommodate her instead. It was only when his friend, the policeman who had come to the house in response to the family's call for help, that Ronald first became aware that Dolores' deviance was a result of mental illness and could in fact be helped.

The medical meaning becomes the principal interpretation of the problem only when it is directly suggested by the police who became inadvertently involved in the crisis, a feature found in Anna's case as well (see 3.1.1 Spiritual-religious framework). In the previous section, I showed how Melvin and James had used normative interpretations of their loved ones' problem. In both Melvin's and James' later search for help, seeking advice from specific people in their social networks who had knowledge of mental illness was pivotal in changing their perception of the problem to a mental/medical one. It is also noteworthy that social ties which were not from their kinship networks were more likely to interpret problems as psychiatric in nature, whereas advisors who were kinsmen had some form of medical expertise.

In three cases, due to the *somatic* presentation of symptoms, a medical doctor was the first person to diagnose the illness, or to indicate that the problem might be psychiatric, but only after the displayed behaviour had escalated in severity and seemed outrightly irrational and disturbed.

In 2002, Siew Min's son Kai Wen believed that he was being followed to and from school. In the weeks that followed, Kai Wen became more and more distressed that there was something wrong with his reproductive organs; he was convinced that someone had found a way to chemically tamper with his sperm and that they were defective. He said he "didn't feel like a complete man" and refused to eat food that was cooked because the "heat would damage his sperm". Concerned, Siew Min took him to a biomedical practitioner at a nearby clinic. The doctor recommended psychiatric evaluation and Siew Min was given a referral letter for a psychiatrist at a general hospital.

Kenneth's son, Eric, had a fainting spell while on holiday with the whole family. A doctor diagnosed heatstroke, but Kenneth took Eric to a biomedical practitioner on their return to Singapore just to be sure. Again, the doctor couldn't find anything wrong with Eric. However, it was when Eric showed clear signs of behavioural disturbance that the problem was diagnosed as a psychiatric one, by the same doctor [19].

Janine, the caregiver to both her younger brother and mother, took her mother to a biomedical practitioner after the latter's protracted complaints about pain in her foot. Thinking that her mother had some shards of glass in her foot, Janine was unprepared and quite shocked to be told that the problem wasn't in her mother's foot, but in her mind. Janine agreed with the doctor's recommendation to send her mother for psychiatric treatment [20].

Amongst all the cases where active help-seeking occurred with the use of a medical meaning, one stood out in that it did not lead to a diagnosis of schizophrenia. In the case of young Kelvin, his mother Chiew Yin recognized the early onset of her son's illness during secondary school and evaluated his behavioural problems as psychiatric or at least psychological in nature [21].

Ironically, despite having sent Kelvin straight to a psychiatric clinic, the first psychiatrist did not diagnose any mental illness, and no treatment was prescribed apart from regular family visits to the Child Psychiatric Clinic ensemble, although the patient was interviewed separately. Kelvin's condition continued unabated and tolerated mainly because his parents perceived his problem as being a function of adolescent rebellion and maladjustment, as his first doctor pronounced, he was simply being "naughty". It was only when Kelvin's behavior became gradually more disturbing and when paranoia surfaced that Chiew Yin suspected that the problem was more serious than mere teenage recalcitrance. Her initial interpretations shifted towards seeing the problem as a mental one when she recognized his behaviour as signs of schizophrenia while reading a newspaper article [22].

The decision to seek psychiatric help was helped by the fact that Chiew Yin's husband was seeing a psychiatrist himself, who urged them to bring Kelvin to her. The importance of social capital – in the valuable and useful social relationships one has – is again observed in being pivotal to the entry to psychiatric care, but consulting someone with the requisite expertise depended on the adaptive shift in one's cognitive framework. I also address how the delaying of help-seeking or treatment affects caregiving.

2.2 The Problem of Delay

The case studies show that months and even years could pass from the first signs of abnormality to the first formal contact with a mental health professional, and that it is not uncommon for patients to pass through several different healers – biomedical and traditional – before receiving the appropriate treatment for their symptoms. Traditional healers such as spirit mediums or traditional Chinese medicine (TCM) practitioners, biomedical doctors (in both private practice and state hospitals) and psychiatrists were the first places that caregivers went to for help. It was found that seeking traditional healers did not result in a longer delay in diagnosis than seeking treatment from a general practitioner even though traditional healing failed to alleviate the prepatient's symptoms. General practitioners tend to be the first to identify an illness which is mental in nature as they usually serve as the first place people go to for primary care (Hunt, 1992). My data showed that of the four caregivers sought help first from a general practitioner, three were persuaded by the somatic nature of their loved ones' problem (physical pain, "defective" body part and fainting). When the symptoms were severe and clearly disturbed, as shown in the cases of Sean and Kai Wen who had delusions of being followed and harmed, the doctor made a quick diagnosis of mental disorder. In the cases of Eric and Mrs Lin as well as Kelvin who first saw a psychologist, the doctors were unable to diagnose any medical or mental abnormality based on what was reported by the patient and caregiver at the consultation. In these instances, the caregivers simply waited until there were more severe signs of abnormality before seeking help again. Doctors tended to normalize or neutralized the problematic behaviour as "nothing wrong" and "very normal for a teenaged boy". Delays in getting schizophrenia diagnosed meant that the patients' conditions had to have become progressively severe before help was sought.

Hence caregivers had to put up with a significant amount of disturbing behaviours of which they had little understanding and few strategies to assist them in coping with these problems.

The persistence of a normative interpretation of insanity could be attributed to two factors: the kinship role and medical uncertainty.

2.2.1 Kinship and marriage role identity

Amongst the cases of delayed psychiatric diagnosis, a profile of these subjects was discerned. The first noticeable similarity was the kinship relation between caregiver and patient. Table I enumerates the number of years elapsing between the recognition of odd behaviour (or "first signs" of an illness) and the first contact patients had with a mental health professional who made a diagnosis of schizophrenia.

Table 3.1

Time elapsing between "first signs" and first contact with mental health professional

Number of Years & Months	*Caregiver/ Relationship to Patient*	*Help-seeking prior to psy diagnosis*
< 1 month	Rina (mother)	Taoist shaman and traditional healer
	Anna (mother)	G.P at polyclinic
	Siew Min (mother)	G.P, state hospital
	Chiew Yin (mother)	Child psychiatrist
	Melvin (father)	Nil
	Kenneth (father)	G.P.
	Janine (sister)	Nil
	Ronald (husband)	Nil
	Jack (husband)	Nil
6 months	Grace (sister)	Private psychiatrist and doctor at state hospital
5 years	James (brother)	Informal consulting of psychiatrist
> 10 years	Janine (daughter)	2 visits to G.P.
	Wei Rong* (husband)	Nil

**Wei Rong, a caregiving spouse did not detect "signs" of abnormality until his wife, Maggie, was forcibly hospitalized.*

Amongst those who were diagnosed within a month of showing disturbing or odd behaviour, six of the eight caregivers were parents, and considering the young age of their children when they first presented with symptoms, we can attribute the short duration between first signs and hospitalization to not only the perceived severity of the problem, but also the role relationship between caregiver and patient, two variables originally hypothesized as determinants of social action. Parents, especially mothers, were more likely to recognize signs of abnormality in their children and appraise the signs as having a medical or mental basis, compared to siblings and children, which is exemplified in the cases of James and Janine respectively.

James, a sibling caregiver, tolerated his older brother Henry's disturbing and distressing behaviour at home for five years before he decided it was up to him to "take action". Janine's story concerns her mother, whose bizarre behaviour had caught her attention since she was a young girl, but more than ten years passed before any attempt to get help was made. Both James and Janine had perceived their loved one's problem as being severe, and just like the parent caregivers, had appraised these signs as having a mental basis. Their inaction was self-attributed to "timing", as both had decided to do something about the problem only when they believed that they were in a position age-wise to act. It might appear that in their cases, their parents who were considerably older may not have had the knowledge to appraise the problem as serious and warranting treatment despite being the primary guardian of the patient. There is evidence that low utilization of mental healthcare has been attributed to a lack of perceived accessibility, need and social stigma amongst Singaporeans' health beliefs

(Choo 1997; Tan et al 2004). However, the parents in my sample who did take swift action had lacked knowledge of mental illness and had held some negative perceptions of mental patients prior to their children's first illness episode. Their willingness to seek help had more to do with the congruence of meanings within the family unit than the role of health beliefs (Gochman, 1995). The construction of meaning about a stressor leading to a coping action depends on the implicit rules of relationships that guide the members of a family in its functioning (Patterson and Garwick, 1994). Family stress theorist Pauline Boss' *boundary ambiguity* construct (1988, 2002) elegantly depicts how strain increases when boundaries defining membership within the family and their role patterns become unclear. This ambiguity was found in Janine's case.

Janine's family had a history of conflict: her parents fought violently and frequently after her father's business collapsed. Her father eventually left the family home to work on a neighboring island in Indonesia, returning to visit once in a while. Janine told me that when one of her elder sisters ran away from home at 15, she and her siblings "blamed her for causing Mum's breakdown". Her mother's depression and poor physical health continued for over ten years until Janine decided to play an active role in her mother's care. "As time goes by, you realize you needed to do something about it when you were older, it was a lot to do with timing." For several years, the family was without its father, whose physical presence was seldom felt yet remained psychologically in the children's memories of violent fights and quarrels, altercations that were reignited each time "Father came home to visit". Boundaries that delineate a clear role structure for each family member had clearly become ambiguous with the absence of their father, the maker of most of the important decisions.

Similarly for James' family, boundaries were also fraught with ambiguity. James said that while he was in the army and later a student at university, he would "lock the door and hide inside the bedroom"; James and his sister and eldest brother "just ignored [Henry] because "I was younger than my brother, and nobody wanted to take action". James' father had passed away when he was very young, and he told me the reason he didn't do anything was because his eldest brother "didn't hold the responsibility as the elder brother. After my father passed away, he was supposed to hold the authority, take care of the family. But he didn't do anything…so we all locked ourselves in our room." When James graduated from university and moved home, he finally decided to do something as he "had finished his schooling" and "was ready to deal with this problem at home". James' eldest brother had also moved out by then, and when I asked him why his mother had not taken any action all this time, James said that she had told him of her "concern" about Henry, but she "was his mother, and she knew him, so she had no fear [of him]". She did not object when James told her he had decided to take Henry to the hospital.

Help-seeking decisions in Chinese culture have been found to be determined by intrafamilial hierarchy and pragmatism (Lin and Lin, 1981; Quah, 1989). The patriarchal structure of the family ascribes decision-making authority based on age, sex, ordinal position and role, social status, experience and knowledge (Lin and Lin 1981: 391). This means that the father or the eldest child (usually son) in lieu of the father would make the final decision on the treatment modality. Younger siblings or children may believe that treatment is necessary, but they may bulk at taking action because of the norms attached to their kinship role in the family. The *responsibility of care* over a sibling or parent may not extend to taking such liberties as taking them to a doctor, much less the onerous decision to commit them to an institution. Young members of the family would defer this responsibility to a parent – the responsibility of care for a child is normatively seen as a mother's role and the care of the mother her husband's – until they are older.

Spiegel (1957) developed a conceptual model for understanding the conflict of roles within the family. Although his discussion did not pertain to hospitalization, his conceptualization has bearing on the process of committing a family member to hospital which involves the "complementarity of [role] expectations" (1957:3) and also a modification of roles within the family. Built upon Parsons' and his colleagues' (1953) theory of action, Spiegel conceived the family as a stable system of roles where a culturally stable pattern of behaviour and expectations leads to a high of stability and harmony within the family's interpersonal relations. In this situation, decision-making is low and action is spontaneous and unconscious. He argues that some domestic roles have to be *achieved*, and conflict might result from an *allocative discrepancy* of roles. Janine and James, both not being the primary caregivers to their mother and brother respectively, were behaving in accordance to their roles, but also avoiding the conscious taking of goal-directed action – a role pattern that each believed was not theirs to play. The reciprocal and complementary expectations inherent in multiple kinship roles within a pre-patient's family may lead one to either initiate a help-seeking action or delay it. In addition to this, the patriarchal element within Chinese cultures makes it noteworthy to consider what Reiss calls “consensus-sensitive” families where members share high levels of consensus on core values and beliefs (1981).

In Wei Rong’s case, his normative interpretation of his wife’s problem led to more than ten years of toleration – he was the only one of the twelve caregivers who had not sought help for his loved one’s problem prior to the event that triggered Maggie’s forced hospitalization at a psychiatric facility. Wei Rong had framed the problem as a intrapsychic one, stemming from their marital relationship and Maggie’s apparent inability to be “happy” [23].

Wei Rong was cognizant of an existing problem, but located it within logic of marital and paternal obligations toward his wife and family, a response informed by his cultural belief about how the “older generation” would behave. The belief orienting Wei Rong’s inaction was one that was connected to the husband/father role that he played, one which was paternal and infused with notions of responsibility towards the family. The discursive content of such a role not only furnished meaning in terms of duties, (“bring up the family, look after the kids”) but also provided a blueprint for performance of those duties. This suggests that Wei Rong’s beliefs about his role obligations explains how he tolerated the situation for such a long time, while his normative perception of Maggie’s nature as a difficult and stubborn woman who didn’t communicate normally didn’t interpret behaviour as illness and discouraged the necessity for seeking help.

2.2.2 Medical Uncertainty

It is likely that in a non psychiatric treatment setting such as the general practitioner’s office, there is high medical uncertainty. A doctor would have to rely on what the patient presents to him during the consultation and to fit that into some medically recognizable pattern. Telles and Pollack (1981) showed that when such presentations are vague and do not appear to evidence any disorder, the patient's complaints tend to be dismissed. Considering that studies have widely supported the positive correlation between the severity and visibility of schizophrenic symptoms and the likelihood of a person being diagnosed as mentally ill (Mechanic, 1968; Zola, 1985), the probability of a general practitioner making the correct diagnosis at the first consultation is very low, especially if the patient's illness has not deteriorated to a serious or acute stage (American Hospital Association, 1972, cited in Alonzo, 1980:515)[6]. For example, Sufficient time had passed since Janine's mother's first visit to the doctor for her condition to show deterioration (severe weight loss and her belief that broken glass was hurting her foot) so that on her second visit to a general practitioner, her adamant insistence that she had a piece of glass in her foot warranted the doctor's suspicion that it might be a somatic delusion[7]. In a similar vein, it was when Kai Wen's beliefs had become so bizarre (that something had caused his semen to be "defective") that his behaviour and beliefs appeared to the doctor to resemble delusions associated with schizophrenia. In the case of Kenneth and his son Eric, the latter had reached what mental health professionals term as a crisis state, where his hallucinations had driven him to such

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[6] By using the phrase "acute stage" (or commonly known in layman's terms as a "crisis") I am referring to one of the phases of the illness trajectory where patients find themselves in an acute illness situation wherein he faces an emergent condition – one that requires immediate medical attention and threatening life or function – or an urgent condition – one that is serious and requires care within hours (American Hospital Association, 1972). Typical acute or crisis situations involve suicide attempts or intention, inflicting self-harm or aggression towards another, or an escalation of psychotic symptoms specified in the "active phase" of schizophrenia (American Psychiatric Association, 1994). I also use Alonzo's (1980) perspective of acute illness behaviour as an emergent health crisis that is perceived by self and lay others as warranting a coping strategy to control or reduce symptoms.

[7] The DSM IV defines delusions are erroneous beliefs that usually involve a misinterpretation of perceptions or experiences. A somatic delusions is one theme among a variety of false beliefs about external reality, specifically concerning pain or changes to the body and physiology (American Psychiatric Association, 1994: 275).

a state of distress and fear that, like the other two cases, the illness signs were severe enough to point to mental illness Eric told his father later that he heard threatening voices in his head). Only when signs of illness had progressively intensified in severity could a general practitioner recognize mental illness as a cause and referred the patient to a psychiatrist.

Misdiagnoses appeared in two cases. Grace first took her younger brother, Jeffrey, to a private psychiatrist who diagnosed Jeffrey as suffering from manic disorder [24]. When Jeffrey did not improve with the medication prescribed to him, a friend of Grace's sister recommended consulting a psychiatrist at Tan Tock Seng Hospital whom she described to me as "extremely kind, listened to us very patiently as I described my brother's condition, and he referred me to this Dr W___. He told me this [Dr W] was a "shen yi" (literally translated from Mandarin as a doctor with magical or godly powers) who could solve all my problems."

In the case of Chiew Yin, she first sought help for her son Kelvin's behavioural problems from a child psychiatrist at a state health institute. The psychiatrist told Chiew Yin that Kelvin was simply suffering from "naughtiness", and it was "nothing to worry about". Still, the entire family went on regular psychiatrist visits with Kelvin for "counseling" despite having no positive answer as to what was ailing Kelvin. For almost two years Chiew Yin observed with alarm that the problem was progressively intensifying. Kelvin was stridently insisting that their domestic helper was trying to poison him, and in one particularly serious crisis situation, he flung the dining chairs at his parents. Chiew Yin's husband had been seeing a psychiatrist for depression at the time, and so after a harried phone consultation with his psychiatrist, Chiew Yin insisted on getting an appointment and took Kelvin to see the psychiatrist who formally diagnosed Kelvin with schizophrenia.

A mental disorder such as schizophrenia is not often a clearly defined disease with uniform symptoms and universally recognizable signs. There is considerable uncertainty in making a diagnosis, and prescribing a satisfactory treatment, and often doctors rely on different hypotheses and solutions, which include normalizing definitions especially where the doctor is not specially trained in psychopathology. (Hopkins and Scrambler, 1977; Mueser and McGurk, 2004) David Mechanic notes that “medical knowledge is a mixture of scientifically precise facts and clinical impressions, leaving much room for medical uncertainty and individual variation to manifest itself in regard to problems patients present to doctors” (1968:23). Renée Fox, in her seminal work on how medical students trained for uncertainty, noted that as students learned to cope with the indeterminate aspects of diagnosis, they had to “commit themselves to some diagnostic and therapeutic hypotheses to take clinical action” (1989: 85). Fox also concluded that to avoid the “undesirable consequences” of undermining their patients’ confidence in them due to medical doubts, students refrained from appearing unsure in front of their patients.

2.3 Summary

In this chapter, I have shown that signs of mental illness, in their myriad and complex manifestations, are rarely immediately interpreted in a psychiatric or mental framework, which falls within the realm of rational, scientific knowledge produced by the medical profession to delineate the concepts of mental illness, insanity and their sources of treatment. On the one hand, community reactions and pressures from societal situations (such as the family and the workplace) reflect, manifest and perpetuate much of the personal and social stigma a patient experiences; on the other, the state and various social agencies are arbiters of social stability, contributing towards the consensus of what is normal or abnormal.

Hence, in Foucault's (1971) view, there is no coherence or singular unity to the concept of insanity because it is the discourse of the professions of psychiatry that delimit the concept of behaviours which are deemed sane or insane. The psychiatric interpretation of abnormal signs is but one *idea* about insanity, ideas which are not only comprised of the beliefs, perceptions and evaluations individuals make of behaviour that falls outside of what is "normal", they are bound up in social ideologies (Ehrenreich, 1978) each with its inherent message which gives meaning and value to the lived experiences of sickness and health.

Clausen and Yarrow's (1955) study of wives of schizophrenic men showed that meanings of insanity were never clear nor did observers have any clear and definitive evaluation of symptoms in a psychiatric framework. Likewise, notions of illness are only understood against notions of health, and signs that deviate from what observers perceive as normality or disorder vary. The normative meanings that caregivers used demonstrate the multiple meanings of abnormal behaviour which led to a range of accommodative practices, showing that delay or temporalizing is a complex process bound by social and cultural ideas. The spiritual-religious meanings described in this chapter illustrate non-medical theories of insanity and alternative healing strategies. These are compatible with medical interpretations in the reactive and pragmatic way that spiritual explanations were used. That said, the medical meaning of illness was often a last resort used by all the caregivers, and was mediated by key social network members or an individual’s active search for answers.

The next chapter studies the meanings of schizophrenia as a medical diagnosis and how they guide the coping patterns in the post-diagnosis phase. I will deal with specific problems of treatment and compliance, followed by how caregivers cope with issues of relapse and recovery.

CHAPTER THREE

THE DIAGNOSIS AND TREATMENT OF SCHIZOPHRENIA

It appears that the role of the caregiver begins with the diagnosis of schizophrenia for it is when a family member is first diagnosed by a psychiatrist that the former is publicly identified as mentally ill. The psychiatric diagnosis signals the shift to a new set of meanings, prescribed courses of treatment and multiple levels of interaction that alters current, past and future experiences. The afflicted person now becomes a certified psychiatric "case" and assumes the role of a patient. This means that relatives not only think of the afflicted person in a new way, but they also take on a new social role: that of a caregiver. It was shown in the previous chapter that in a few of the cases, there was a long delay of up to ten years between the first signs of illness and first contact with a mental health professional who made an official diagnosis of schizophrenia. I acknowledged that coping actions came into play during these interim periods of uncertainty, but the pronouncement of the medical diagnosis brought a new level of awareness to these caregivers. Rather than experiencing an abrupt change in role, this signaled a renegotiation of their role vis-à-vis their loved one: the latter was now a mental patient.

This chapter examines (1) the new caregiver's response to the psychiatric diagnosis and (2) how he or she coped with the immediate stressors related to medication when the patient was discharged from hospital. The first section examines the caregivers' understanding of the psychiatric label, and their beliefs and expectations about recovery from mental illness. The first section explores the triad of interactions between caregivers, patients and physicians leading up to diagnosis, and the way caregivers responded to the diagnosis schizophrenia. I will show that in many cases, inadequate information about the illness and the lack of a clearly communicated diagnosis resulted in confusion and anxiety in coping with a loved one's need for special care. The second section explores problems related to the treatment of schizophrenia. I use the concept of self-regulation to explain how such strategies functioned to give patients and caregivers control over their medication practice, the problem of side effects and coping with situational exigencies.

3.1 Coping with the schizophrenia diagnosis

A wealth of medical sociology research indicates that symptomatic behaviour is open to varying interpretations. Upon contact with a mental health practitioner, what was initially for the lay person an agglomeration of unconnected or mysterious complaints or odd behaviour becomes an "organized category of disease" (Balint, 1957) with a prescriptive course of action for treating the disease. What was previously believed to be "bad-temper" is now a "symptom of schizoaffective disorder".

When I asked the caregivers specifically what the diagnosis of schizophrenia had *meant* to them, and how it had made them feel, I found that the question was interpreted in different ways. Three issues connected to the diagnosis of schizophrenia will be presented: the first is the way in which they received the diagnosis, which in more than half the cases was confusing and fraught with questions and uncertainty. The second issue concerns the caregivers' interpretations of their loved one's role as patient. I argue that *expectations* of recovery that caregivers had, shaped their response to problems both quotidian and exceptional. The third issue deals with the emotional reaction to the diagnosis of schizophrenia.

3.1.1 Inadequate or incomplete understanding of "schizophrenia"

When a loved one was hospitalized and treated for mental illness, the caregiver hardly ever knew with certainty "what was wrong". There were mainly two ways of "receiving" a diagnosis, the first was a clear pronouncement of the problem – schizophrenia – which was communicated by the psychiatrist to the caregiver (in the cases where the patient was in abject denial of his illness, the psychiatrist discouraged the caregiver from informing his loved one); the second, more common scenario was one of ambiguity: the caregiver was not given a clear explanation of what the patient was suffering from and only through subsequent relapses, visits to different physicians and information through other channels that the caregiver got a fuller picture of the illness. The following cases illustrate the second scenario where the lack of a clear diagnosis affected the caregiver's understanding of the problem, and how he or she subsequently coped with the patient.

Ronald's first experience with his wife Dolores' illness was in 1976, shortly after they married. He only realized it was schizophrenia several years later when she suffered a severe relapse. After her hospitalization, Ronald knew only that Dolores' condition was a kind of "mental illness" [25]. She continued to show symptoms in the years to come, but Ronald was unaware that they were signs of schizophrenia until the next serious crisis. Although research has shown that drug therapy is the most effective approach in the prevention of relapse (Lehmann, 1975; Tsuang, Faraone and Green, 1999; Mueser and McGurk, 2004), caregivers are often caught unaware when the drug fails and the patient continues to manifest symptoms despite being on medication. In addition, the stabilization of a patient depends on the degree of symptom control and the side effects of the drugs (Mueser and McGurk, 2004). Sometimes, the patient might have other mental disorders (known as comorbidity) like depression occurring together with the schizophrenia which requires drug control as well. Hence, a combination of regimens and dosages to stabilize the symptoms is necessary but tenuously achieved, as depicted in Ronald and Dolores' case. In Ronald's words, it took him and his wife's psychiatrist "months and months to get her dosage just right."

Wei Rong's case is different from the others in that he did not suspect that his wife Maggie was ill until she was forcibly taken to the state mental hospital. In Chapter Three, I explained how Wei Rong's case illustrates the use of a normative framework to understand the loved one's strange behaviour. He interpreted his wife's behaviour in terms of her "difficult" personality and had tolerated her behaviour as something that couldn't be helped. Wei Rong was unable to say if anyone had diagnosed Maggie with schizophrenia [26]. Wei Rong continued to attend the follow-up consultations on Maggie's behalf when she refused to go. But he told me that each encounter with the psychiatrist was mainly his own private therapy session: "Once every month, he's just like every other psychiatrist, always smiling, saying "very interesting". It was like my chance to air my grievances to someone, for my own relief!"

Wei Rong read up on mental illness, and it was after he made an emergency call to the Institute of Mental Health hotline that he was given some very helpful information about getting help from a private ambulance. He was referred to the Singapore Association of Mental Health (SAMH) which runs a free 12 week workshop for caregivers of close family members with severe mental illnesses. The SAMH social worker told him his wife's symptoms fit the diagnosis of schizophrenia.

When I asked the twelve caregivers individually if after the medical encounters they had understood what their loved ones were suffering from, I received mixed answers. Siew Min, looked a little uncertain when she said: "He didn't tell me anything, just said it was *jing shen bing* (Mandarin for "mental illness"). No details. Later the psychiatrist asked him if he heard noises. He (psychiatrist) didn't tell us much; he just told me it was mental illness, that I was to give him medicine."

The case of Grace is similar. Her brother was misdiagnosed by the first psychiatrist. The second psychiatrist diagnosed her brother with schizophrenia and emphasized the importance of taking the prescribed medication. Grace explained: "Dr W___ told us that my brother's illness is *tian sheng de* (Mandarin for "born with it"). He explained to us that the illness had to do with the brain, that something cannot connect or something…. The medication will help [the brain] to connect properly. So this was our understanding at the time."

3.1.2 Assumptions about "recovery" from schizophrenia

The care of a schizophrenic patient largely involved doing what was necessary in aiding his recovery and overcoming problems that were either a direct or indirect result of his mental illness. The normative interpretation of being sick and being well was inherent in the narratives of the caregivers when they spoke about their loved one's first discharge from hospital, illustrated in cases where caregivers spoke of how, after a period of close monitoring and medicating, they assumed that the patient "had recovered" or "seemed well enough to stop the medication". They had observed improvement in their condition, notably the receding of the most disquieting symptoms like hallucinations and disorganized behaviour. The return to normalcy, signaled by the patient's regaining of his or her pre-hospitalization functional ability was perceived by these caregivers as an indication of recovery. This corresponds to assumptions of how a patient should behave in the medical sick role. However, the differences between a medical and mental patient sick role makes it difficult to level the same kind of role expectations on a mental patient (Erikson, 1957; Gallagher, 2002).

After complying with the prescribed medications for an average of six months, Melvin, Chiew Yin and James believed their loved ones had "recovered" or were "cured" of schizophrenia. Hence, they stopped giving medication to the patients. Their reasons for believing this were largely due to the fact that at the time, they had "no knowledge about mental illness", or did not know that the treatment of schizophrenia required long-term medication. For Melvin and Chiew Yin's children, going off their medication for half a year resulted in the recurrence of symptoms. For Melvin's daughter Sharon, the incessant trips in and out of the bathroom at night became regular again, along with insomnia which kept the family up at night. Chiew Yin's son Kelvin became irritable and withdrawn and on one occasion, had lashed out at his sister by kicking her. Similarly, James' brother Henry took a turn for the worse after James stopped medicating him. James had always mixed the medication in Henry's food, until he "became too busy with work to apply the medication". When this happened, Henry's problematic behaviour recurred again. "He would bring home these dirty things, you know these idols from outside, he himself had no hygiene…by then all his teeth had rotted and he wasn't eating properly. Later on when I asked him, I realized that he was hearing the voices again, he thought the religious idol things could help him [vanquish] the voices and the visions," James said.

The problem for caregivers with medical sick role expectations stem from two factors: (1) differences between the characteristics of medical and mental patients and (2) the relationship between physician and patient, which is usually less reciprocal for mental patients and requires the participation of a family member, usually the primary caregiver. Firstly, the schizophrenic is often ambulatory and prognosis is initially uncertain. Very often, schizophrenia patients experience a bumpy recovery trajectory, where their illness is often chronic and prone to recurrence (Sobel and Ingalls, 1964; Hawley, 1997; Gallagher, 2002). There is thus no clearly defined state of recovery from the illness itself.

3.1.3 Reactions to the "schizo" label

Emotional reactions included shock, dread, and how they had misjudged their loved ones, while the cognitive reactions were mainly questions about the cause and possible outcomes of the illness. The emotional reactions suggests that respondents already had preconceived notions of what mental illness was, and their emotions belied certain negative beliefs about mental illness. Shock, devastation and even a sense of surrealism were some of the emotions described by Siew Min, Melvin and Chiew Yin [27, 28, 29].

Chiew Yin's dismay at learning of her son Kelvin's schizophrenia diagnosis came across most poignantly among all the interviews. When I asked her why she believed that schizophrenia was "a horrible illness", she told me it was something "with a lot of stigma” and from what she had read upon being given the diagnosis, that it was “really frightening” and a “great blow” to her son. Chiew Yin feared that the social stigma of mental illness would affect her son’s future and his ability to cope independently. Her lament – “what will become of him?” – reveals a perception of the mentally ill as people who face inevitable social rejection, leading to the inability to lead fulfilling lives. The emotional responses felt by parents of the mentally ill in Chinese societies have been described as a complicated mix of emotional self-blame and moral shame of having tarnished the family name in the eyes of observers, due to their perception that they as family members had failed to prevent the illness befalling their loved one (Lin and Lin, 1981). The husbands, Ronald and Wei Rong, on the other hand, were contrite at having misjudged their wives’ behaviour prior to realizing that it had been mental illness [30, 31].

Karp (1996) describes diagnosis as a double-edged sword. On one hand, it is a relief for family members as the medical label signifies the possibility of treatment and an absolution from personal responsibility, but problematic on the other, because of the social stigma and an erosion of one’s self-worth. This dilemma is consistent with studies that show that the therapeutic benefits of treatment may in fact be diminished by the adverse consequences of being labeled mentally ill (Link, et al. 1997; Rosenfield, 1997). The diagnostic labels “schizophrenia” or “mental illness” are by no means universally understood or accepted, but rather they conjure amorphous images of dreaded outcomes which are bound to a specific locality and history. In Singapore, stereotypes of the mentally ill abound: a decrepit-looking maniac wandering the streets, a hysterical or dangerous criminal (historically associated with *amok*[8]), suicidal jumpers from high-rise buildings and television portrayals of the ubiquitous straitjacketed (usually violent) asylum inmate. Such frightening images of the mentally disordered instill shock and disbelief among the patients' family members.

Four of the parent caregivers had to deal with an emotional onslaught of recrimination from their loved ones. The three mothers, Chiew Yin, Anna and Rina found themselves on the receiving end of their sons' wrath at being committed to the mental hospital, while Kenneth and his wife were blamed by their son for causing his perceived social failure. Anna's son Sean treated her with acrimony when she first had him admitted to the mental hospital for treatment [32]. Sean believed that electro-convulsive therapy (ECT) had damaged his brain. In fact, Anna went as far as to believe the same, blaming herself for acquiescing to the second psychiatrist's recommendation that ECT be performed on Sean. The husbands, Ronald and Jack, were equally not spared from recrimination and anger, which they said had been the worst at the beginning of every hospital admission [33, 34].

Compounding the emotionally stressful task of getting their loved ones treated was struggling with the question of why this had happened. For mothers Chiew Yin and Siew Min, it led to tremendous self blame when they searched for causal factors. Siew Min believed for a long time that she may have caused Kai Wen's illness when she dropped him as a child while breastfeeding him [35]. Chiew Yin was unable to care for her son after his birth because of her health, and believed that her inability to bond with her child had effects on his illness onset as a teenager [36].

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[8] Amok is known as a sudden, acute outburst of unrestrained violence which was associated with homicidal attacks. It is preceded by a period of brooding and ends with physical fatigue and amnesia. See Yap (1951; 1969), Tan (1965), Carr and Tan (1976) and Teoh (1972).

Gender was not a distinguishing factor as kinship relation amongst the caregivers who had feelings of self-blame and guilt. In fact, the parents, both fathers and mothers, alluded to some personal responsibility for their children's illness [37, 38, 39]. Anna and Rina felt their husbands' behaviour – neglect and physical punishment respectively – had contributed to their sons' problem, while Melvin attributed cause partially to the pressure he had given his daughter to continue with work and studies in spite of her reluctance. Siblings Janine and Grace also alluded to conflict or tension within the immediate family being partially responsible for their loved ones' condition [40, 41].

The propensity to retrospectively scrutinize family members, particularly parental actions, for blameworthiness is common for close relatives of mental patients (Terkelson, 1983; Harden, 2005) and explains the immense guilt that these six parents felt for believing they had failed in some capacity in their children's upbringing. Janine believed that her "violent family" history contributed to her brother's illness. And similarly, Grace told me that her parents might have "shown disappointment or disapproval" in her brother Jeffrey who had not "gone as far as they expected of him". The mothers, Rina and Anna, attributed their husbands' parental styles and behaviour toward their sons as contributing factors. The references to psychological traumata connected to a parent's deficiency or over-involvement is a common etiological belief held by lay persons (Furnham and Chan, 2004). However convinced they might have been of such explanations, the caregivers' sense of the past and future had been disrupted by the diagnosis of illness.

3.2 Coping with the Treatment of Schizophrenia

The intransigent problems of refusals to accept treatment or reluctance to comply fully with the treatment regimen called for a host of strategies from making overt threats to covert tactics. Younger patients who were in their teens when they were first diagnosed were reluctant to accept medication because they did not understand or could not accept that they had a mental illness. Sharon, Kelvin and Zihai had to be cajoled or threatened with punishment while Sean, Eric and Kai Wen (who were a little older, in their early twenties) were more steadfast in their refusal of medication. In fact, they vehemently denied they had mental illness in the beginning while Sean went off his medication to avoid social stigma. He believed that the side-effects of the drugs would slow his speech (because he had observed another schizophrenic who appeared to speak more slowly than normal) and render his problem visible to others. Of the older patients, Rina's mother, Mrs Lin and the three wives, only Maggie denied she was ill and refused to take medication. Jeffrey and Sam (whose primary caregivers were their siblings) accepted medication and Henry, James' brother, accepted his illness two years after James began secretly administering his medication.

3.2.1 Strategies to medicate the patient

Melvin, whose daughter Sharon was six when she first "saw people who weren't there", struggled with discipline issues all through her teenage years. His strategy combined reasoning and threats to have her "locked up" at the mental hospital or banished to a home [42] as he felt Sharon "doesn't listen to anyone when she's in a bad mood".

Others tried to reason or used some kind of compulsion. Kenneth's son Eric had been going off his medication and denying that he had a mental illness. He only agreed to go back on his medication because his parents reasoned that he needed drugs just like anyone suffering from a chronic physical illness [43]. Both Melvin and Kenneth appealed to their children by equating being "normal" with social functioning. Having physical freedom and mobility was important to their children. Sharon was "very independent" and "didn't like it if she couldn't have money to go out" and Eric wanted to continue his university studies in spite of his illness. To them and their caregivers, medication meant a ticket to normality, a capacity to be and interact within a normal social environment.

Collusion with doctors was common when it came to a strategy of getting help for a patient who refused to take medication. Chiew Yin resorted to collaborating with another biomedical doctor to get her son to take the medication he initially refused after his first relapse. When Kelvin went to a dermatologist for his acne, Chiew Yin convinced the doctor to prescribe Kelvin the anti-psychotic pills without his knowledge [44].

Wei-Rong was introduced in Chapter Three as the middle-aged husband and father of two young sons. His wife, Maggie, was legally admitted to the Institute of Mental health in 1994 after a public skirmish. Maggie had initially refused to go to her appointments with her psychiatrist. Wei Rong went to see him without her for a few years and has been unable to get Maggie to stay on her medication. This has led to multiple relapses because of her inconsistent medication compliance [45].

James, another caregiver, also consulted the psychiatrist on behalf of his brother, who had refused to admit he was mentally ill. James views his interaction with his brother's psychiatrist as a valuable and instrumental relationship as he believes Henry's psychiatrist had gone beyond ethical boundaries to prescribe medication despite having never examined Henry in person [46]. He had agreed to prescribe the necessary medication based solely on James' account of Henry's condition due to Henry's refusal to see the psychiatrist.

Getting the required medication involved negotiation with psychiatrists, particularly when the patient refused to even step into a clinical setting. The caregivers engaged in an instrumental exchange and negotiation with mental health personnel. The psychiatrist's clinical assessment of the patient in such cases relied on the caregiver's account of the absent patient's condition. Reporting their observations was the only recourse left to the spouse, sibling or parent who was in desperate need of medication for their loved ones.

For some patients and their families, the diagnosis might give meaning to the disorder and may result in greater personal and emotional control. It was possible that lacking prior knowledge about schizophrenia had a less traumatizing effect on the caregiver receiving the news, regardless of his or her age. However, the consistent lack of information about the illness led to misconceptions in some cases, which culminated in rehospitalization. Compounding the situation was the fact that many of the patients lacked the capacity to understand their mental condition, a common occurrence in schizophrenia patients (Amador, Strauss and Gorman, 1991; Rose, 1988). Green (1988) found that 44% of people who were frequently hospitalized for psychiatric care denied they had mental illness, and this denial corresponded to their refusal to medicate. Gerhardt (1989) believes that without the patient's acceptance of the diagnostic label, diagnosis would fail to have much positive influence on his behavioural conduct, self-perception and the ensuing illness trajectory. Therapy occurs in two settings, the home and the hospital. She points out that the management of treatment implies an active role accorded to the patient, but I would add that this is heavily mediated by the primary caregiver. Although their caregivers tried valiantly to ensure that the medications were consumed – either secretly administering them in food or using other strategies – caregivers often didn't have complete control over the regularity of medicine consumption. Some patients lived apart from their family and chose not to adhere to the regimen while some others refused to consume "spiked" food when their suspicions were roused. James said of his brother Henry: "Sometimes he tastes the food a bit funny, he throws it away."

When patients denied their psychiatric condition, or were adamant that they did not need medication, my findings indicated that this hampered their recovery and made it more difficult for their caregivers to prevent relapses or to cope when the symptoms recurred. However, going by the current literature, "non compliance" inadequately explains what happened in the course of medication practice amongst my sample of cases. From the medical perspective, those who conform to their doctor's orders are "compliant" (Lorber, 1975) or obediently fulfilling obligations of their "sick role". Appelbaum and Gutheil (1980) studied inpatients at a psychiatric hospital and classified non-compliant patients in three categories: those who occasionally refused because of some situational reason; those who refused because of paranoid or delusional beliefs related to the medication; and those who simply wanted to exert their right to refuse medication. This explanation oversimplified the matter and emphasized the perspective of the medical professional more than that of the patient. From the perspective of the patient, the issue did not only concern either denial or acceptance of their illness. In addition, the aforementioned studies were carried out on inpatients, while outpatients or schizophrenics who lived at home with their families face different kinds of situational contingencies than hospital inmates. Patients and caregivers face a whole different set of issues that concern the *practice* or use of their prescribed medication (Schneider and Conrad, 1983:190) and it would be limiting to presume that a patient's obduracy alone explains their lack of cooperation in this regard.

The next section focuses on caregivers who knowingly deviate from the prescribed medication regimen. Rather than take the medical perspective of "non-compliance", I use Schneider and Conrad's (1983) concept of "self-regulation" to explain why patients and caregivers deviate in the practice of medication. Although each case of self-regulation appeared unique, the variations could be organized into several patterns or "types" of self-regulation in the consuming of medication.

3.2.2 Strategies for self-regulation

Although medication as a form of treatment is generally accepted as instrumental to the control of symptoms and to reduce the risks of violent or erratic behavior in public, it is also well-known that this strategy is not foolproof and drugs often have limited efficacy. Someone who takes his medication regularly may still hear voices, while another who stops his medication for a time or reduces the dosage according to what he feels is needed can go on without disturbance. Given the spectrum of disorders within the category of schizophrenia (American Psychiatric Association, 1994) as well as the broad range of symptoms for each type and coupled with the range of physiological reactions each individual has, to specific brands of medicines, caregivers spent time shuttling back and forth to the attending psychiatrist and sometimes to many different physicians before they got the medication “just right”. Schneider and Conrad studied epileptic patients who “self-regulated” and specified three exclusive but not limited criteria for this practice: (1) to reduce or raise the daily dosage of prescribed drugs for a period of time; or (2) to skip or take extra doses under specific circumstances (like coping with “stress” or when driving); or (3) to stop taking the drugs completely for three consecutive days or more (1983: 184). I found that in all twelve cases I studied, caregivers chose at least one of these self-regulation strategies at one point, although the deviation period ranged from as short as one day to as long as one year. Based on my observations in this study, I add two more indicators of self-regulation: (4) when caregivers went to their physicians seeking changes or adjustments to the medication and (5) when caregivers sought alternative forms of therapy or healers.

I offer three explanations for self-regulation strategies: the management of medication side effects, the perception that the prescribed medication was ineffective and adapting to a situational contingency.

Managing side effects

Side effects of anti-psychotic medication were a common reason for adjusting or changing medication practice. Sean and Kai Wen refused to take medication to avoid the side effects, which tended to slow their speech, cause drowsiness or poor concentration. Melvin stopped his daughter Sharon’s medication because he had believed she was well and didn’t need the medication any longer, and partly because he felt “too much medicine [was] no good for the health”. In Rina’s case the drugs had caused her son to have side effects to the point of impaired social functioning, and she returned to the psychiatrist or sought other means of help. When caregivers turned to the psychiatrist, the doctor usually prescribed a different drug or an altered dosage. I use Rina's case to highlight the social dynamics of finding the appropriate care when medication caused more problems for the patient than it did in ameliorating his condition.

Rina's son Zihai had what fits the DSM-IV's description of delusions of persecution as well as auditory hallucinations (American Psychiatric Association, 1994). After Zihai was sent to the emergency room at the Institute of Mental Health (IMH), he was referred to the Child Guidance Clinic, a branch of the IMH which specializes in adolescent and childhood mental illnesses. Rina told me about the slew of complications following treatment [47]. Rina's anxiety about the side effects of her son's medication was in part due to his adverse physiological reaction (sweating, shaking hands, and the lump on his nipple) and partly due to what she perceived as the inherent harm of long-term drug consumption. She believed that "medications are not good for the liver and kidneys" from the books she had read and the seminars she had attended.

The belief that long-term dependency on medication is negative is a lay belief that is wide-spread among the twelve subjects in this study. In traditional Chinese medicine (TCM) practice, it is believed that "Western" medicine has negative residual or side effects for the body when consumed over long periods. Rina is an example of an active and avid user of traditional healing practices who believes that traditional medicine helps alleviate the harmful effects of radiotherapy and chemotherapy amongst people undergoing cancer treatment. Janine, who cares for her younger brother and mother who both suffer from schizophrenia, told me that her mother refused to let her and her siblings take medication as they were growing up because “she believes that…you know the Hokkien saying “lai” … they believe Western medicine does more harm than good for the body.” Janine attributed her brother’s skipping his medication to her mother’s beliefs about Western medicine.

Returning to Rina’s case, the problem of side-effects was becoming incrementally severe, to the point where her son Zihai was becoming impaired by them. She sought help from a psychotherapist and a psychiatrist in private practice who had been highly recommended by her brother while still keeping to Zihai’s physician, Dr. S___. The psychotherapist explained the nature of Zihai’s illness and advised her on ways to help him. One of them was seeking another psychiatrist’s opinion, which led her to Dr. Y___, a renowned private psychiatrist whom her brother had told her of [48]. Rina took Zihai to see Dr Y___ when his condition worsened. Dr. S___ was on leave, and Rina was galvanized by the perceived severity of Zihai’s symptoms to go to another psychiatrist, bringing Zihai’s medication along and telling him about his problems with medication. Zihai improved with a new medication, and Rina told me she had no regrets about seeing another psychiatrist because it may have saved Zihai from a serious crisis [49].

It has been shown in several studies that treatment refusal or (self) modification of dosage is determined by the impact of negative side effects (Van Putten 1974; Kane, 1983; Cournos, McKinnon and Adams, 1988).

Perceived Treatment Inefficacy

The perception of efficacy has a major role in how caregivers responded to their psychiatrists’ orders. In the previous section, it was shown that caregivers stopped medications when they perceived that the patient was no longer symptomatic and perceived as having “recovered”. However, the perception that a drug or treatment was ineffectual or was causing more harm resulted in the search for a different solution. The perception of treatment inefficacy was also exemplified by dissatisfaction with the psychiatrist’s prescription of drug therapy. Grace changed psychiatrist while Rina sought help from a private psychiatrist and a psychotherapist. At the time of writing this thesis, Rina informed me thar she had asked for another psychiatrist because she was “utterly fed up and disappointed” with Zihai’s current psychiatrist. In Anna’s case, she terminated her son’s treatment because she felt it was doing more harm. She told me that she regrets the treatment that a private psychiatrist she had sought help from had given her son:

When a community psychiatric nurse (CPN) from the Institute of Mental Health (where Sean was first admitted to) visited Anna’s home and told her about schizophrenics being susceptible to multiple relapses if they didn’t adhere to their medication, Anna admitted she panicked because Sean had refused at the time to take his medication. Anna called a private psychiatrist for help. The private psychiatrist convinced Anna that her son had become “chronic” although the DSM-IV (American Psychiatry Association, 1994) specifies that 2 years’ history of illness was required for chronic status to be applied. Furthermore, the doctor had based his assessment entirely on Anna’s recollection of what had happened. Fearful that Sean would end up like the “chronic patients” at the mental hospital, Anna was convinced by Dr. W___ that electro-convulsive therapy would help Sean without posing much risk of detrimental side effects [50].

Sean’s condition did not improve after Anna transferred him to the private hospital. After speaking with Sean’s former psychiatrist, she terminated his ECT treatment and had him transferred back to Woodbridge Hospital. Furthermore, she professed to feelings of extreme guilt for having taken that action and regrets allowing the ECT treatment to be performed on him [51].

Wechsler (1983) points out the myriad treatment approaches and persuasions of mental health professionals as a source of frustration for many families of the mentally ill. Lefley (1987a:10) terms this a “dilemma” for families who are faced with a choice of therapeutic interventions[9] but are not provided with reliable criteria for evaluating them.

In Wei Rong’s case, he went to his wife’s psychiatrist appointments on his own and regulated her dosage himself, slipping it into her food, but with limited success. He continued to grapple with her multiple relapses and the symptoms that continued despite such efforts [52].

Wei Rong doesn’t regard the psychiatrist as someone who could instrumentally aid in his wife’s rehabilitation. As he sardonically puts it, they would smile, humour him and prescribe medication. Instead, he chose to reframe each consultation with the psychiatrist as his personal therapy session, using his own strategies for coping with Maggie’s persistent problems [53].

Wei Rong continued to medicate his wife, and to get her to go to her medical appointments for her injections even though he believes that “Chinese medicine, western medicine and even acupuncture could not cure mental illness.” Instead, Wei Rong subscribes to an entirely different paradigm of illness etiology. I asked him if he thought the mental health profession was helpful for someone with Maggie’s condition, and he told me that professionals played an important role giving “support” but that the drugs they prescribe were not in themselves effective [54].

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[9] For example, supportive vs psychodynamic therapy; medication-free vs a regimen of neuroleptics; outpatient vs inpatient; brief vs long-term hospitalization. Psychosocial rehab in community setting vs individual therapy with psychiatrist.

Spiritual healing came into play when it became apparent that the medication could not provide a bona fide cure for the patient’s illness. This happened in Melvin’s case. Sharon was first hospitalized and treated for schizophrenia by a psychiatrist. When her symptoms receded after six months, Melvin took her off the medication, thinking she had recovered. When Sharon’s symptoms returned, Melvin believed that the medication had not worked, and turned to a number of spiritual healers who each had different explanations for what was causing Sharon’s illness.

Melvin contracted the services of a number of spiritual healers, whose proffered solutions included the “exorcism” of demons and spirits, geomancy (or “feng shui’) practices and changing the location of his ancestral tablets to “appease” them. He “converted” to Buddhism in the process, and continues to “pray to Guan Yin” (a Taoist deity known as the Goddess of Mercy) [55]. Spiritual healing was a cultural resource that was used by Melvin as a strategy to find a permanent solution while the anti-psychotic drugs only offered a temporary alleviation of Sharon’s symptoms.

From the cases presented, the psychiatrist often represented one out of an array of sources of help, and the prescription of medication was one out of many strategies for managing persistent problems.

Situational Contingencies

A situational contingency is an unexpected or atypical event that has caused or might have potentially caused an inordinate amount of stress on the patient, resulting in a relapse or worsening in the severity of symptoms. Under such circumstances, Rina, Jack and Ronald decided to self-regulate, to manage the potential risk of their loved one becoming more ill.

In two cases, caregivers spoke of adjusting dosages in situations of “high stress”. Rina increased Zihai’s dosage when she observed his condition worsening as his school exams approached, and reduced it again after the exams [56].

In the case of Jack, the other retired teacher who is married to Carina, 44, her pregnancy was the reason she went off medication. According to Jack, Carina “stopped taking the medication on her own” without his knowledge for nine months, the whole time she was pregnant. She had a relapse after giving birth and had to be admitted to a psychiatric facility.

The sudden and rapid onset of a crisis typifies another kind of situational contingency that required self-regulation strategies. This was exemplified by the patient experiencing an acute schizophrenic episode or “breakdown”. During a particularly distressing episode, Rina’s son became extremely agitated and had started to hurt himself, threatening suicide. In the face of crisis, Rina tripled Zihai’s medication, believing that an increased dosage would “calm” him down. It worked; Zihai calmed down and she managed to coax him into seeing the psychiatrist [57].

In the case of Ronald’s wife Dolores, a national health crisis in 2003 – the Severe Acute Respiratory Syndrome (SARS) epidemic – caused Dolores (who had been receiving in-patient treatment at the Institute of Mental Health at the time of the event) to be separated from contact with Ronald for a week. When a spate of mysterious fevers broke out in one of the wards, it precipitated a hospital-wide quarantine. For the two weeks Dolores was separated from her husband, she was beside herself and believed that Ronald had abandoned her for another woman. After the lifting of the quarantine, Ronald decided to have Dolores discharged against the medical advice because on top of her schizophrenic delusions, her emotional state had worsened during isolation in the hospital [58]. Terrified that she would become more depressed and distraught if she remained in hospital, Ronald insisted that Dolores' undergo the electro-convulsive therapy she still needed as an outpatient instead of staying in hospital [59].

These cases show that disparate but sudden events brought about the necessity to intervene for the sake of the well-being of loved ones. Self-regulation strategies were used in each case as a response to the contingency. Examining the data carefully, it became apparent to me that failure to conform to the prescribed treatment regimen had less to do with the doctors than to the patients' and caregivers' need for regulation or control. If we discount the recalcitrance of some patients and caregivers' initial lack of knowledge about the nature of schizophrenia, we can see that their decisions to stop or alter the medication practice had to do with their beliefs about the costs and benefits of medication, the perceived inefficacies of medicines (and getting the right combination of dosage and regimen) and the daily contingencies of managing the patient in the home and community. Medication is hence perceived as instrumental to the control or prevention of symptoms, to reduce the social risks of violence and above all, to insure a balance of normality of social and personal functioning. The preservation of "normalcy" was paramount to the patient's well-being, in the opinion of caregivers, both as a means to prevent social stigma from observers and a strategy to encourage self-confidence. Those who self-regulated did so to get greater control over the difficult and debilitating process of achieving normalcy.

3.3 Summary

From what I have presented in the previous sections, the medical diagnosis could potentially give credence to medical conditions, legitimizing the patient's suffering. On the other hand, societal beliefs about the mentally ill coupled with normative presumptions of being "well" run counter to reality for many recovering patients, culminating in a delegitimized status. In addition, caregivers were initially unaware of the nature, course and long-term effects of the illness as doctors tended to emphasize instructions on medication over the nature and prognosis of the illness. Diagnosis had far-reaching consequences, for the control of the illness itself and for the management of a new social identity. Cognitively, caregivers had to manage their expectations by changing preconceived notions about the mental patient sick role. The strategies used by caregivers to negotiate with healthcare personnel and with the patient in the aftermath of diagnosis further evidences the difference~~s~~ in sick-role between the mentally ill and other types of patients. Finally, the management of treatment can be understood as a host of strategies, depending on the resources available to the caregiver. Self-regulation is one of them. Cultural resources which are pivotal to furnishing the interpretive meaning of using medication comprise beliefs (religious or sociocultural), advice, information and social support. In other words, I argue that in any situation, *culture as resource* helps caregivers select and adopt a strategy like self-regulation as an *adaptive response* to the situation. The medical profession's definition of "compliance" does not fully explain the complexities of treatment adherence. Treatment decisions are better explained in the context of the caregiver's beliefs, priorities, pragmatic considerations and unexpected situational demand that shaped the ways in which caregivers coped with medication issues.

CHAPTER FOUR

THE STRUGGLE FOR NORMALITY

I have described how the issues of diagnosis and treatment were coped with in Chapter Three. This chapter explores caregivers' strategies in managing the care of their loved one upon coming home from the hospital. This stage of coping is defined as the process of attaining as normal a level of social and occupational performance as most other adult members within the community. With their loved ones undergoing treatment as outpatients, caregivers now cope with two kinds of problems in this stage of the mental patient's sick role: averting or managing medical crises, as well as activities of daily living such as work and social functioning and self care which includes taking medications and participating in psychotherapy. However, problematic behaviours are protean in nature, usually exacerbated during the early stages of illness and showing improvement as the illness is stabilized by therapy, thereby potentially calling for caregivers to modify their expectations and demands on the patient. Therefore, to account for this variation in patient behaviour, I asked the question: "***Let's talk about a typical day when [patient's name] is not having a relapse. In your opinion, what would be the things he can do for himself on a good day versus a not-so-good day*?**" Finally, to get a good picture of the range of "normal" social functioning, I asked the question: "***On a normal day, what would you say are 'good things' and what would be a 'bad thing' that [patient's name] would do or experience?***"

The patients typically showed two kinds of sick role behaviour: acute symptoms also known as a "breakdown" or medical crisis, and chronic, non-acute symptoms. The former refers to severe or urgent conditions that require medical care (American Hospital

Association, 1972 cited in Alonzo, 1980: 515) or perceived as an emergency crisis situation (Alonzo, 1980) by family members of the patient. In the latter non crisis situations, the patient’s behaviour was deemed bizarre or difficult by the caregiver. These kinds of behaviour could be either periodic or persistent everyday problems, and some patients manifested both, causing a great amount of anxiety for the caregiver whose patience underwent strain. These behaviours were categorized into three types of abnormal behaviour, which are presented in three sections. The first section examines strategies for emergent crisis situations; in the second section I examine strategies for managing the patient in the performance of the basic functions in everyday life: self-care, domestic chores, work or social activities.

4.1 Coping with crisis situations

At first glance, life at home for the twelve caregivers and their loved ones was a hotch-potch of daily hassles, occasional crises and chronic anxieties. Every patient had played different family and social roles to varying degrees of passivity and significance before their illnesses. Hence these myriad role factors culminated in a combination of different problems for each caregiver when their loved ones were discharged from hospital (see table 4.1). Most of patients were able to perform activities of daily life with adequate function, such as dressing, hygiene, eating and getting about on their own, while others could not be entrusted to be on their own for fear that they would “get into trouble outside”. Some caregivers struggled with violent or uncontrolled behaviour that arose intermittently, while others had to deal with these problems only on several occasions.

Table 4.1 Types of Difficult Behaviour (acute and chronic)

	Difficult Behaviour	**Persistent**	**Intermittent**	**Very occasional**
Psychotic or acute symptoms	Extreme anger or behaving violently toward self or others (includes paranoid beliefs)		Zihai (Rina's son), Kelvin (Chiew Yin's son), Sean (Anna's son)	Kai Wen (Siew Min's son), Sharon (Melvin's daughter), Carina (Jack's wife)
	Talks to oneself or nonsensically and other irrational or uncontrolled behaviour.	Henry (James' brother)	Kai Wen (Siew Min's son), Maggie (Wei Rong's wife), Mrs Lin (Janine's mother)	Kelvin (Chiew Yin's son) Carina (Jack's wife) Jeffrey (Grace's brother)
	Argumentative, verbally abusive.	Henry (James' brother) Mrs Lin (Janine's mother)*	Sharon (Melvin's daughter), Carina (Jack's wife), Eric (Kenneth's son)	Jeffrey (Grace's brother)
	Harasses or gets involved in altercations with relatives or others not within household		Sharon (Melvin's daughter)	Jeffrey (Grace's brother)
Negative or compulsive symptoms	Withdrawn, uncommunicative or isolates oneself at home.	Eric (Kenneth's son), Maggie (Wei Rong's wife), Zihai (Rina's son)	Mrs Lin (Janine's mother), Jeffrey (Grace's brother) Carina (Jack's wife), Kai Wen (Siew Min's son)	Kelvin (Chiew Yin's son), Sam (Janine's brother)
	Anxiety, excessive fear or depression, suicidal tendencies		Dolores (Ronald's wife) Sharon (Melvin's daughter) Zihai (Rina's son)	Carina (Jack's wife)
	Obsessive and compulsive behaviour	Kai Wen (Siew Min's son) Sean (Anna's son)	Dolores (Ronald's wife)	
Responsibility to self and others	Problems with sleep and appetite (not eating or eating too much) or substance abuse	Henry (James' brother) Jeffrey (Grace's brother)*	Mrs Lin (Janine's mother) Sharon (Melvin's daughter)	Henry (James' brother)
	Problems with personal hygiene (not bathing, lax oral hygiene)	Sharon (Melvin's daughter) Henry (James' brother)	Kai Wen (Siew Min's son)	
	Not complying with medication or therapy	Maggie (Wei Rong's wife), Kai Wen (Siew Min's son) Henry (James' brother)	Kelvin (Chiew Yin's son), Zihai (Rina's son) Mrs Lin (Janine's mother)	
	Unable to manage finances or overspends	Sharon (Melvin's daughter) Carina (Jack's wife)	Henry (James' brother)	Carina (Jack's wife)
	Refuses or unable to do household chores or generic tasks (grocery shopping, paying bills)	Sean (Anna's son) Eric (Kenneth's son) Maggie (Wei Rong's wife)	Kelvin (Chiew Yin's son), Henry (James' brother)	Carina (Jack's wife) Dolores (Ronald's wife)

For the host of difficult behaviours encountered by each caregiver, both acute and chronic, maintaining the patient at home required different strategies to be adapted to different kinds of situations. There were four kinds of coping strategies in response to both severe and non severe symptoms. I noted *preventive strategies* where the caregiver used vigilance to spot early signs of a relapse and took action to circumvent a crisis as well as *accommodative strategies* where the caregiver waited for the disturbing behaviour to abate while trying not to exacerbate the situation; *proactive strategies* were responses to crises where the caregiver took immediate action (the decision to take the patient to hospital is one such action); *internal coping* describes strategies for coping with the caregivers' own emotional reactions to difficult and demanding situations. Internal coping evidences the stress and turmoil experienced by a caregiver and is a valuable resource for coping with uncertainty and long-term impairment.

"Periodic psychiatric hospitalization is an inherent component of treatment for persons diagnosed with such major psychiatric illnesses as the schizophrenias or the bi-polar affective disorders" (McElroy, 1987: 61; see also Mueser and McGurk, 2004). All twelve caregivers said their greatest fear and concern throughout their loved one's illness was the onset of a relapse. The released patient's long-term community tenure has been regarded as a key indicator of successful rehabilitation because of the frequent occurrence of the revolving door syndrome (Freeman and Simmons, 1963; Davis, 1975; Geller, 1992). This describes patients who discontinue their medications or stop seeking treatment (or both) once they are released from hospital, leading to the recurrence of severe symptoms that precipitate hospitalization. Once he is stabilized and again released into the community, the cycle repeats itself. Non compliance with medication has been documented as the primary cause of recidivism to inpatient hospitalization (Scheidcook, 1987; Fernandez and Nygard, 1990; Delaney, 1998; Lim, et. al. 1995). The cases of relapses triggered by medication non-compliance described in Chapter Four agree with these observations, however, multiple hospital readmissions were common in only five of the patients – three of them older women with the longest histories of schizophrenia (see Table 4.2). Wei Rong, Rina, Chiew Yin, Anna, Melvin, Kenneth, Ronald and Jack each recalled at least three episodes or more of disturbing behaviour during the entire tenure of their loved ones' illness since diagnosis.

Table 4.2 *Patterns of relapses and rehospitalization after diagnosis*

Caregiver/ Relationship to Patient	*Patient, Age*	*Number of years from diagnosis to December 2005*	*Number of hospital readmissions since diagnosis*	*Number of severe episodes* of relapse recalled by caregiver*
Janine (sister)	Sam, 32	4	0	0
Rina (mother)	Zihai, 18	2	0	3
Siew Min (mother)	Kai Wen, 27	3	0	1
Chiew Yin (mother)	Kelvin, 30	12	0	3
Melvin (father)	Sharon, 23	5	>6	>6
James (brother)	Henry, 44	15	1	1
Janine (daughter)	Mrs Lin, 64	11	1	1**
Anna (mother)	Sean, 26	2	2	4
Grace (sister)	Jeffrey, 30	5	2	2
Kenneth (father)	Eric, 34	15	3	3
Wei Rong (husband)	Maggie, 49	11	>5	>5
Jack (husband)	Carina, 44	23	8	Too many
Ronald (husband)	Dolores, 53	36	7	Too many

* Does not include "borderline" situations where caregiver took action to avert a potential crisis.

** Janine described her mother's condition as having deteriorated between 1994 and 2001. She recalled one severe episode of hallucination while the "weird, disturbing behaviour" continued constantly throughout this period.

4.1.1 Accommodative Strategies

Accommodation was used by three caregivers during situations which they perceived as very severe or unmanageable. The result was avoidance of forcibly hospitalizing their loved ones and maintaining the status quo in the home. The following cases of Wei Rong, Anna and Chiew Yin epitomize the practice of accommodating a symptomatic patient.

Wei Rong, Maggie's husband

The "most frightening" experience Wei Rong encountered was the night Maggie picked up a large cleaver, left the house calmly and started attacking a lamppost at the foot of their apartment building. Paralyzed with fear, Wei Rong began to meditate, an effort which made him "completely tranquil". Maggie returned shortly with the knife bent out of shape. Still shaken, Wei Rong wondered if he should call the police, but Maggie appeared composed and was speaking lucidly. The family returned to what they had been doing as if nothing unusual had happened [60].

Wei Rong admitted that he hadn't always known what to do when Maggie showed disturbing symptoms. He would simply "bear with it". Reasoning with her was futile as "she didn't care, it wasn't her problem, she didn't care about anything she did." This was in part exacerbated by Maggie's erratic medication compliance and her reluctance to go to her doctor. Wei Rong resorted to an *internal coping* strategy just as he accommodated Maggie's occasional flare-ups. His spiritual beliefs not only provided him an emotion-focused coping resource (meditating) during these distressing moments, but extended to an explanatory theory of mental illness. Wei Rong felt it was futile to ask for help in times of crisis. His accommodation of Maggie's problematic behaviour came to a head only recently, when Maggie's behaviour exerted an even greater strain on the family. On several occasions of relapse over the last five years, Maggie would call contractors to the home to dismantle and dispose of the furniture. She would change the locks, and a week before my first interview with Wei Rong, had placed an advertisement to sell the apartment. At night, she would sneak out to report her husband of abuse at the police station.

At the height of distress, when Wei Rong was feeling “so lost”, he called the Institute of Mental Health’s crisis hotline for help. It was that call for help which precipitated a change in his response to Maggie’s problem, as Wei Rong learned that he could call a private ambulance to take Maggie to hospital whenever she became unmanageable [61]. Wei Rong’s accommodative practice was initially due to his lack of personal and social resources to manage Maggie’s disturbing behaviour. Information about where to get help in such distressing situations became a vital social resource for Wei Rong after his SOS call. He has been using the private ambulance service during Maggie’s relapses ever since.

Chiew Yin, Kelvin’s mother

Chiew Yin encountered serious situations when her son manifested disturbing and sometimes violent behaviour. On one occasion, Kelvin dressed himself up in his sister’s clothes and became extremely agitated and aggressive. When he left the house abruptly in a skirt, his long hair up in a ponytail, Chiew Yin admitted she was at a loss of what to do. She refused to call the police, despite her daughter’s urging, because “as a mother, [she] didn’t have the heart to do it”. A few nerve-wrecking days passed before she called the Singapore Association for Mental Health for help, and was advised to call an ambulance for Kelvin if he became unmanageable again [63]. Chiew Yin went to the hospital to see the psychiatrist on Kelvin’s behalf, and administered the liquid medication into his food. She described each incident where Kelvin “lost himself” as moments when she would get “very, very, very scared”. On a separate occasion, when Kelvin lashed out at someone during group therapy, Chiew Yin, who was waiting for him found herself “paralyzed” with fear. “I thought I was going to have a stroke there and then!” Kelvin was “okay after that”, he told his psychiatrist that someone had said something to anger him. Chiew Yin experienced a dilemma between restraining Kelvin by force (with police intervention) and her maternal impulse to protect him. Like Wei Rong, she didn’t believe police intervention would help her son, but at these times, she also didn’t have access to social resources that would get Kelvin to a treatment facility.

Anna, Sean’s mother

Anna found herself having to manage a violent crisis at home one night when her son Sean flew into a violent rage after his elder brother provoked him by stabbing his arm with a screwdriver. Incensed, Sean grabbed his father’s martial arts sword, trying to beat the door down to get to his brother. His parents could not placate Sean who was impervious to their pleas to put the sword down. He finally relented when Anna offered him money to back down [62].

Anna seemed to have a workable strategy for managing Sean’s rage. She told me that bribing Sean with money was the only effective solution to get him to take his medication, go to therapy and generally get him to do anything. Anna’s accommodation appears to work because Sean responds to the reasoning and bribery. He has only been hospitalized twice and Anna told me she believed he was recovering well.

Caregivers chose accommodative strategies for two reasons: they didn’t know of any other way to cope with the crisis or their loved one was resistant to treatment. Social support helped Wei Rong and Chiew Yin by pointing them to a valuable coping resource (private ambulance) in times of crisis.

4.1.2 Preventive Strategies

A particularly intractable problem the caregivers faced was when a loved one became irrational and unmanageable. Caregivers who felt helpless or threatened usually thought of police intervention, although none of the twelve caregivers had actively called the police. This was usually done by the patient at the height of his paranoid delusions. The emergency room at the mental hospital could not respond to caregivers in distress by dispatching an ambulance unless their loved ones were registered patients of the hospital. It was only in 2004 that a Mobile Crisis Team (MCT) was set up as part of the hospital's pilot initiative for dealing with such problems in the community. Unfortunately, the MCT, comprising an ambulance, paramedics and a community psychiatric nurse, operates only between 8.30am to 6pm from Monday to Friday (Lim, et. al. 2005). Most of the crises that beset the caregivers occurred at night.

The caregiver who believed that his loved one required immediate medical attention tended to perceive the situation as a "relapse" or "breakdown" and this interpretation of the meaning of illness signs hinged greatly on the caregiver's tacit knowledge. Tacit knowledge was used by all the caregivers in managing the onset of a relapse with the noticing of little "warning signs" or the perception that their loved one was "becoming unwell" or "borderline". The caregivers would notice changes in the patient's mood or behaviour, and over the next couple of relapses, they began to become sensitive to even subtle aberrations or significant events that might "trigger" a relapse. This time, the caregiver was much more adroit at recognizing the early signs of illness. The ability to recognize when a loved one was "on the verge" of a relapse led to the use of *preventive* measures – the strategy of medication regulation was most common (discussed in Chapter 4), followed by reducing demands on the patient. For instance, when Chiew Yin noticed mood changes in her son Kelvin, she would not ask him to do any chores but would “just leave him alone”.

Every one of the caregivers told me that they had come to realize that there were several “triggers” that would precipitate a relapse. The most common triggers were traumatic or stressful events. Ronald had sent Dolores, his wife, to hospital seven times in the past three decades, each time following a major crisis that had been preceded by a stress-inducing event – a death of a close family member, the onset of Dolores’ menopause and SARS in 2001 which resulted in a hospital quarantine and the isolation from her husband. Rina’s son Zihai, as well as Kenneth’s son, Eric, experienced relapses soon after starting their studies. Rina attributed Zihai’s most recent breakdown to his inability to cope with his newly commenced Polytechnic course. Kenneth tried to encourage Eric to quit his university studies after the first relapse, but Eric refused.

Another type of trigger was the lunar seventh month, or the month of the Hungry Ghosts, where according to Chinese traditional belief, the ghosts of one’s ancestors are freed from “hell” to roam the earth for a month. Melvin saw a correlation between this time of the year and Sharon’s relapses, as “every year during the seventh month, she will relapse”. As a consequence, Melvin would be extremely vigilant during the months of July and August where the “ghost month” typically fell.

A person within the family with whom the patient has trouble getting along was also a trigger of illness behaviour. Chiew Yin’s son Kelvin would become very “jealous” and unstable whenever his sister visited from overseas. Chiew Yin would be much more “observant” at these times. Anna told me both her sons had always been “at loggerheads”, and that Sean would get much better if his brother “got married and moved out”. The brothers’ fights had culminated in Sean’s crises in the past.

4.1.3 Proactive Strategies

A typical proactive strategy of coping during crisis was to take the patient to the hospital for treatment immediately. This was easily done in the cases of acquiescing patients such as Dolores (Ronald wife) and Carina (Jack’s wife) who both understood and accepted that they needed help. However, Rina was the only caregiver who had been proactively managing her son’s severe relapses right from the beginning. Rina did not have her son, Zihai hospitalized albeit having suffered three relapses in the two years since his diagnosis. Each relapse was characterized by violent outbursts and attempts at self-harm, and Rina scrambled each time to get Zihai under control. Rina’s strategy was to self-regulate Zihai’s medication (see Chapter 4) and to coax him to calm down and see his doctor. She actively sought help from her psychiatrist and her son’s social worker (at the aftercare centre). Of particular import was the psychiatrist who gave Rina the go-ahead to modify Zihai’s medication dosage each time he suffered a severe relapse.

During the most recent relapse, Rina came home to find Zihai kneeling on the floor speaking incoherently, a small knife hidden under his knee. Fearful that he could become suicidal, she phoned his psychiatrist and was advised to increase his medication dosage [64].The increased dosage of medication did not have positive effects on Zihai. Two days later, there was a violent incident, and once again Rina chose to self-regulate (see Chapter Four) Zihai’s medication in favour of hospitalizing him. Once again, she chose to consult her psychiatrist in favour of taking Zihai to the hospital because she believed that Zihai would be even more distraught if she tried to hospitalize him because he “hated [her]” for “causing his illness”. He had become highly irrational, his delusions causing him to believe that Rina had been in collusion with his voices to harm him [65].

4.1.4 Emotion-focused and spiritual coping strategies

Five of the caregivers spoke of either religious beliefs or the managing of their emotions to cope with the long-term toll that their loved ones’ illness had taken on them.

Wei Rong’s emotional coping strategy is connected to his spiritual beliefs. According to Wei Rong’s *Falungong* belief, the universe consists of multiple dimensions where the human mind possesses a potentially pure state known as the “True Self” or “main consciousness” which can be diluted, weakened or interfered with by artifacts from another “dimension”, the underlying cause of mental illness. He thereby feels that psychiatric treatment has its limitations in helping Maggie overcome her illness. This belief about Maggie’s affliction helped Wei Rong perceive her behaviour in a symbolically meaningful way, one in which it became logical to accommodate Maggie’s needs as well as the demands she made on his patience and wits.

Wei Rong’s way of interpreting the meaning of his wife’s illness has notable consequences for how he has chosen to relate to his wife, as it enabled him to effect a change in himself, even if he feels he cannot do much more to ameliorate his wife’s condition. Whenever Maggie’s delusions take hold, berating Wei Rong in front of relatives or asking for a divorce, he copes by managing his emotional response to his wife, remaining calm rather than “get angry or feel embarrassed” [66]. For Wei Rong, his experience of overcoming great stress reinforced his own spiritual beliefs as well as exacting a profound change in perspective towards caring for his wife:

> In the beginning I thought marriage was supposed to be….I was disappointed. It turned out to be something like heaven which became hell later. So I was very…dissatisfied with this. But since learning about Falunggong, having these beliefs, I have realised the

> meaning of life, of love, that I must complement what the other lacks. Marriage is a chance for a few actors to play a part on stage, to see if we can coexist in tandem. Same with healing: it's not so much about imparting knowledge that is superficial. It's about understanding, *ti hui* (empathizing) you know? In my thirties, I didn't understand what I was here for, what life was about, so I got very angry and I had so many reasons for being angry. But we shouldn't get angry. [Wei Rong]

In Jack's case, he told me that in over twenty years of marriage to Carina, he had learnt to cope with every bout of Carina's relapse by "going over everything that happened, and asking myself what I did wrong, and how to improve next time". He describes his resource as a markedly greater store of patience and a change in his "worldview" [67].

For Melvin, James and Rina, their spiritual beliefs served an adaptive coping function when the limits of therapeutic efficacy had been reached. In Melvin's case, making peace offerings to the dead spirits of affronted ancestors, "cleansing" the house of malevolent "spirits" and changing the positions of the furniture made sense because at that time Melvin believed that supernatural causes were connected to Sharon's illness. Even though these strategies proved ineffective, and medication became the mainstay for managing Sharon's symptoms, Melvin and his wife continued to observe the religious ritual of prayer to the Guan Yin deity in the hopes that it will safeguard Sharon's wellbeing [55]. Rina used a similar resource: she has been a dedicated disciple at her regular Buddhist temple and even got her son Zihai to participate in the prayer rituals on occasions. She told me Zihai "does the ritual of praying on his own now" and that even though he is still symptomatic from time to time, she believes this has helped him become "more calm" and "hearing less voices and not getting so easily agitated by them".

James' spiritual-religious beliefs served an adaptive function for coping with brother Henry's condition, who, like Wei Rong's wife, had become chronically impaired. He believed that if Henry became a Christian and accepted "prayer healing", it would prevent the "dirty things, demons, from going into his head". James blends two different illness meanings to explain his brother's mental illness – the spiritual-religious and the biomedical interpretation. Being a Christian from the highly charismatic Pentecostal denomination, James also had an affinity to Chinese folk religions of which the spirit world of demons and deities are an integral part. He eschews the biomedical theories of schizophrenia in favour of the spiritual one even though he concedes that medication is indispensable for keeping Henry's voices and visions at bay.

This grafting of western sectarian beliefs onto an indigenous system of folk beliefs is neither new nor uncommon in Singapore (Goh, 1999). James' pragmatic acculturation (Quah, 1989) of the spiritual-religious and the biomedical serves to explain two different problems: the fundamental problem of illness aetiology and the secondary problem of managing the symptoms. These diverse supernatural theories of causation are based on specific cultural beliefs, and the spiritual and quasi-religious beliefs belong to the *spiritual-religious illness meaning*, which can be understood as a cultural heuristic device for making sense of illness causation. Teoh (1973) showed that symbolic interpretations like that given by a shaman or a Pentecostal "healer" are paradoxically more "concrete and compact" than biomedical explanations, and are more easily understood and accepted by a client within that cultural background (1973: 58). Although attributing causality to "demons" or interference from "other dimensions" suggests a fatalistic value orientation that has been perceived as a barrier to effective crisis management (Boss, 1988), this illness meaning directed three caregivers towards purposive courses of action.

4.1.5 Summary

Social resources played an important role in all the strategies used for coping during a crisis. Anna and Rina had supportive and trusting relationships with their sons' psychiatrists who were sources of support in times of need because of their willingness to call their psychiatrists for medical advice. Information was a key factor that helped alleviate some of the stress of being faced with a crisis. The caregiver support group was their main source of information and social support, along with crisis hotlines run by the same organization and the Institute of Mental Health. The attendees exchanged notes on their respective psychiatrists, made valuable "contacts" on which psychiatrists were "good" and got information on crisis management where they were encouraged to use "non conventional strategies" to either get their loved one into treatment or to "convince" a medical officer (an MD in training for psychiatry) at the emergency room to admit their loved one. These social networks provided information resources that were critical to coping in future crisis situations.

4.2 Managing "normality"

Apart from the control and stabilization of the most acute symptoms, the social and occupational performance of a patient is regarded as most important in the rehabilitation of a mental patient. A recent study of schizophrenia and general practice outpatients in Singapore revealed that schizophrenics had significantly poorer social and occupational abilities (Tan, et. al. 2004).

In this study, the thirteen patients were expected by their caregivers to function at some level of normality and this entailed performance of certain tasks related to the care of himself and to a limited extent, that of others at home. However, the performance of role responsibilities in every day life was in many of the cases hampered by the patient's chronic problems. Social isolation and a general lack of interest or motivation can be a negative symptom of schizophrenia as well as a side effect of certain anti-psychotic drugs (American Psychiatric Association, 1994). In all twelve cases, the most common and persistent problems at one time of the illness or throughout it were the patients' refusal to socialize or leave the house, do household chores or find employment, and to take medications. Caregivers who found their loved ones beset with this kind of behaviour were often frustrated because the patient would "refuse to do anything" he was asked to do.

The family or kinship role played by the patient was related to the degree of anxiety expressed by each caregiver and the extent they went in getting their loved ones to perform according to expectations. The amount of responsibility in the home accorded to the patient varied between two extremes: on one end, some patients were expected to help with chores and return to some semblance of their former life, such as being gainfully employed; on the other extreme, the patient was not expected to work or help with chores and tasks. Davis and his colleagues (1957) had observed that higher tolerance of deviant behaviour in parental families compared with conjugal families resulted in longer community tenures for sons and daughters with mental illness rather than husbands or wives. Two years later, two of the authors replicated the study to validate another proposition: that female caregivers – mothers more than wives – had lower expectations for their mentally ill kin which resulted in lower posthospital performance (Simmons and Freeman, 1959).

The myriad strategies used in the three types of role performance which involved responsibilities to oneself and others in the family: (1) activities of daily living (ADL) or self-care including care of the home; (2) social functioning which comprises participation in activities with friends or relatives at home and outside; and (3) work or occupational function are influenced by a balance of expectations and demands by caregivers. The twelve caregivers began with a mixed balance of role expectations and demands at the outset – seven of them can be described as having low expectations and insisting very little on their loved ones' performance, while the other five can be described as having high expectations for their loved ones and insisting strongly on their performance. However, comparing caregivers' expectations of the patient's "normal" functioning is considerably harder when they were at different points along their loved one's illness trajectory during the interview period. Expectations varied between the period when the patient was discharged for the first time and when the patient had had multiple relapses and discharges from hospital, leading to changes in demands made on the patient. Hence, I collected information on patient and caregiver role performance at two time points, asking first, "***Could you tell me what you specifically did for [patient's name] during the first few months since he was first diagnosed or discharged?***" followed by, ***"Could you tell me, as [patient name's] caregiver, what are the things you specifically do for him now that he cannot do for himself?***"

At the end of the illness trajectory which they were asked to recall – which ranged from 2 to 36 years (see Table 5.2) – most caregivers had modified many of their previous beliefs and expectations for their loved ones' performance. These alterations appeared to be due to the patients' inability to fulfill their caregivers' expectations.

4.2.1 Activities of daily living

The ability to care for oneself – taking medication, personal hygiene, proper eating and sleeping habits – was largely fulfilled by most of the patients. Problems with food and hygiene became serious only when the patient experienced symptoms of illness, in the case of Mrs Lin (Janine's mother), Henry (James' brother) and Jeffrey (Grace's brother) when they lost weight rapidly during the period they defaulted on medication. However Sharon, 23 and Kai Wen, 27, had an aversion to taking baths and Sean, 27, didn't eat or sleep normally because he was a "computer game addict" according to his mother. Melvin uses "force" to get Sharon to observe proper hygiene while the mothers, Anna and Siew Min, tried a combination of accommodative and reasoning strategies [68, 69, 70].

Medication was another issue of self-care that some caregivers found themselves having to manage. The supervision of medication would typically be the responsibility of the females. Mothers would "supervise" their children's medication intake, probably because the care of the family's health is a socially-defined role which is assigned to women more than men in the Singaporean family (Quah, 1990). Janine and Grace did the same for their mother and brother, and after Jeffrey's mother died, his sister would make sure that Henry's medication somehow got into his food when she paid her weekly visits. Anna had the most persistent problem with her son's medication because of his erratic compliance. Hence, she resorted to bribing him. She admitted that it was the only way she knew to get James to take his medication and to go to counseling. She agreed with Sean's counselor that she had been too indulgent and permissive by giving him money, and stopped when the counselor urged her to. Sean has refused to go back to counseling as a result [71].

Performing household chores and running errands was a demand that few caregivers expected of their loved ones. It was very uncommon in the parent caregivers, Chiew Yin and Melvin being the exception, and more common in sibling caregivers. In Seng's (2005) study of caregiver burden, perceived and actual support was found in members of the immediate family, and this was particularly observed in spousal dyads where the mother of the sick wife would step in to take over her role. Seng asserted that the fear of social stigma prevented the caregiver from seeking help from sources beyond the immediate family unit (2005:114). This finding is partially supported in the narratives of the husband caregivers, although all three husbands did not cite family support – from their own immediate family as well as their wives' – as being present to alleviate the tasks formerly performed by their wives. Allocation of domestic tasks in the cases of the husbands and wives had been based on the husband/breadwinner and wife/caregiver roles since marriage. The husbands had to take over the role of home and child care when their wives were unable to perform adequately, usually in the periods preceding and following a relapse.

Wei Rong's case illustrates the burden of multiple caregiving and social roles [72]. Wei Rong's problem was likely exacerbated by Maggie's refusal to see a psychiatrist or take medication. Her frequent relapses prevented her from fulfilling her role obligations. In addition, there is a reluctance to seek support from his siblings or relatives from the assumption that this would be a burden on his siblings who have their own nuclear families.

For the parents, Anna, Rina, Kenneth, and Siew Min, their sons' unwillingness to help with chores was not perhaps, entirely due to their illness. They had not been expected to perform these tasks prior to their illness. The patients' mothers took on the most responsibilities for the care of the household. In addition, Anna and Rina appeared to have the least support from their husbands [73, 74].

Melvin, Janine, Grace and James were the caregivers who insisted that their loved ones fulfilled their responsibilities in the area of self-care and household chores. Not only did they have high expectations of the patient's performance, the strategies they used were based on mutual reciprocal exchange and discipline. Melvin resorted to strict discipline measures in order to get Sharon to do her chores, go to the day center and to generally keep her behaviour in check. When he caught her smoking in the toilet, he "beat her" on the arms to get the message across [75]. Melvin has relatives living nearby, and although Sharon had a penchant for running to her maternal grandmother "when she wants money" or "when she gets angry when I beat her", Melvin discouraged his relatives from stepping in to help as he believed it would encourage Sharon's rebellion [76]. Sharon would become manipulative and highly disruptive whenever she was near a relapse. His strategy was to "control" Sharon's behaviour with overt force or coercion because he felt she needed to "be afraid of somebody" or she would try to wreak havoc on the family, refusing to behave or go for rehabilitation at the day care centre [77].

Grace, unlike Melvin, described caring for her brother as a "family effort". She and three other siblings who live in the same neighbourhood share the task of making sure Jeffrey gets to school, comes home to do the chores, get his meals and sleep. Grace takes Jeffrey to the MRT station in the morning, after school he goes to another sister's for lunch and a nap; when he returns home, his eldest sister (whose family also lives there) makes sure he does the sweeping up and cleaning. Grace makes sure he takes his medication at night and sleeps before midnight. Using a combination of vigilance and advice, Grace managed to get Jeffrey's compliance even though "he doesn't like it here in Singapore and wants to go back [to Malaysia]". Grace and her siblings use a highly vigilant style of managing Jeffrey, where supervision is pivotal in preventing instances of erratic behaviour where Jeffrey is wont to wander off and get "into trouble". Although this strategy stops short of Melvin's strategy of control and coercion, both caregivers practice active strategies to get their loved ones to adhere to their demands for self functioning.

James and Janine both encouraged their loved ones' self functioning in exchange for financial support. In contrast with many of the parent caregivers who did not make demands for role performance, James and Janine were not as accepting of a highly dependent relationship. In fact, Janine and James managed the flow of assistance to their brothers through negotiated exchange. James used to give his brother money whenever the latter demanded it as Henry could never hold down a job. After attending the caregivers' support group and learning about the nature of schizophrenia as a disorder and the side effects of antipsychotic medication on patients, James stopped insisting that Henry find a job but negotiated an arrangement that was agreeable to the both of them [77].

Janine stopped expecting her brother Jeffrey to find work, for he would have vomiting spells every morning before work. Janine "trains" him to do household chores and run errands; in exchange, she gives him "pocket money as incentive" [78]. Janine also gets her mother to do something at home, such as cooking, which Janine simplifies for her [79]. It is through such a mutual exchange of support that Janine tries to ease her loved ones towards a daily pattern of normality. She believes that getting them to do some kind of housework does more for their confidence and recovery than languishing in bed all day. On "bad days" however, they would "laze" in bed all day, not doing anything. Janine admitted that this was probably brought on by emotional imbalances like depression, and she would have no choice but to leave them alone.

The siblings expected their loved ones to do things for themselves rather than "lazing at home all day" and used strategies to encourage such role performance. Janine's mother and brother, as well as James' and Grace's brothers had not suffered a relapse since being discharged from their last hospitalization. However, lapses were unavoidable when the patient had a "bad day" and the maintenance of normality in daily life had to be continuously performed by both the caregiver and patient through "assisted effort".

4.2.2 Social functioning

One of the most endemic problems in restoring normality to a mental patient's life is the normalization of social interaction with people outside the household. This is clearly an obstacle to recovery as social interaction is an integral part of psychosocial rehabilitation. Patients who isolated themselves at home or are averse to interacting in the community or with outsiders (non family members) tend to reject daycare centres, support group meetings, counseling and other kinds of therapeutic activities. Five of the twelve caregivers revealed that social support and disclosure of their loved ones' illness to family and friends were helpful in encouraging the normalization of social functioning. The rest did not find interaction with kin and social networks useful perceived the likelihood of social stigma from those who "didn't understand mental illness".

The case of James and his brother Henry illustrates an active strategy of encouraging the patient towards normal social functioning. James got Henry to convert to Christianity shortly after his hospitalization and began to include Henry in his social networks to "encourage him to socialize and build up his self confidence". James had disclosed his brother's illness to one of two friends at church, and was told that Henry could be "demonized". They encouraged James to get his brother into "prayer healing". This spiritual belief, coupled with supportive friends, spurred James to include his brother in his own social networks [80]. James believed that Henry's self-consciousness about his illness made him reluctant to socialize, so to reassure him that he had not divulged his secret, James stayed away from Henry's "cell group" members. If Henry felt "positive" about himself, he would be more confident and socialize more. "Keeping demons at bay" and boosting Henry's self-confidence became new goals over full recovery.

Jack and Rina found that disclosing their loved ones' illness to their colleagues and friends helped in coping with relapses as well as social rehabilitation. In Jack's case, friends offered social and instrumental support whenever his wife had a relapse [81]. Rina's friends, siblings and even a neighbour befriended her son, offering "encouragement" and getting Zihai to feel less uneasy about interacting with others [82].

Formal support from a community health provider paved the way for Janine's mother's rehabilitation. A social worker was responsible for getting her mother into a day care centre, and rather than use coercion, Janine promised her mother that she would not have to stay in hospital any longer if she agreed to go to day care [83].

The caregivers who did not list social support as helpful had encountered social rejection or perceived social rejection in the community and workplace. The case of Anna illustrates this [84]. Sean was ostracized by people at their church after it became known that he had been hospitalized for schizophrenia. The same happened with Anna's colleagues when she took him with her to work after his discharge from hospital. Sean has since refused to return to church or socialize with anyone else (he has no friends of his own) and Anna felt helpless as she "cannot make people accept him".

The belief that neighbours or friends would not understand their loved ones' illness led to these caregivers' reluctance to disclose the illness to family or neighbours. The most common rationale is the belief that others would not be able to help and the perception that their loved ones may be stigmatized [85, 86].

In their study of parents and spouses as caregivers, Anderson and Lynch (1984) found that caregiving led to a restriction in social activities and often reduced the caregiver's social network. Similarly, MacCarthy (1988) observed that caregivers tended to remain isolated in their own homes with few social contacts. Kuipers et. al. (1989) argued that the stigma attached to mental illness increased caregivers' social isolation, leading to a decrease in potential sources of support.

Caregivers who did not perceive social stigma from their family, friends or neighbours found that disclosing their loved one's condition or confiding in certain members of their social network gave them positive rewards. Chiew Yin, Siew Min, Wei Rong and Ronald had chosen not to disclose their loved ones' illness to non family members out of perceived social rejection rather than having experienced stigma themselves or through their loved ones. However, other caregivers found that disclosure brought tangible benefits, particularly from supervisors who were supportive during a crisis. Simmons' qualitative work (1965) showed that when patients and their family chose to divulge their condition or hospitalization, the community mobilized to help them through economic and instrumental ways.

4.2.3 Work and occupational function

A common premise in much sociological literature has been that work is the purposeful activity consistently expected of a healthy adult male individual. The cultural evaluation of work is reflected in the medical profession's definition of physical and psychiatric rehabilitation whose principal emphasis is in the restoration of occupational ability (Cohen, 1988). Studies in the occupational careers of mental patients have approached hospitalization as the disruption of and interference with a patient's occupational career. However, in reality, many patients either had not been employed before their illness because of their young age or had erratic career patterns where they had not been able to keep a job for long periods due to their illness. Only three of the patients in this study, Sam, 32, Kai Wen, 27 and Sean, 26 had been actively working at the time of their schizophrenia onset. In all the other parent-child dyads, Sharon, Eric, Kelvin and Zihai were diagnosed with schizophrenia in late adolescence, before they had

had a chance to join the workforce. In the sibling dyads, Henry and Jeffrey had similarly never worked prior to their illness.

Of the three wives, Dolores and Carina had worked for less than two years in their early twenties before a severe relapse permanently ended their careers. Dolores never worked thereafter and Carina quit two subsequent jobs because of her illness. Fearing another relapse after the second time Carina resumed work as a laboratory technician, her husband and caregiver Jack persuaded her to quit permanently. Carina had a tendency to take her work seriously, and would inevitably become “stressed” each time she went back on the job. Noting that stress was a trigger of her illness, Carina herself would only now participate in part-time, voluntary work. Recently, her boss at the Salvation Army where she volunteered twice a week offered her a full time position. Jack told me she turned it down, preferring “not to give myself the stress”, in her own words. Jack, like the other husbands Ronald and Wei Rong, had never expected his wife to work. “I am able to provide for her and the family, so there was never a need for her to work”, said Jack.

It is common among Singaporean families to see men taking up the primary responsibility for economic support as part of their husband-father role. The man’s occupational role is considered crucial especially when his wife, being afflicted by mental illness, is unable to work. Moreover, the family’s social status is largely determined by the job of the household head and his income (which is also influenced by his education) than by any other indicator (Quah, et al. 1991). A single male, would come under less pressure than a married male to secure and keep a job, particular if he lived with his family of orientation and if there were other breadwinners in the household (ibid, Simmons and Freeman, 1959). I was unable to find any caregiver cases in which the patient was the husband-father/breadwinner. All schizophrenic males in this study were single, and all the patients who were married were females. Therefore, parents of adult children had to grapple with the problem of their children's inability to find paid work. Male patients in particular were more "vulnerable" in the area of occupational impairment. Unlike the married female patients, they are unmarried and cannot depend on a spouse for long-term financial support. Tan et. al. (2004) suggested that the narrower social and occupational functioning of male schizophrenia patients compared to females might contribute to their poorer quality of life.

All six caregivers who are parents expressed worry about their children's ability to fend for themselves when they or their spouse pass away. Initially, parents expected their children to find employment after a period of stabilization. However, apart from Kai Wen, Eric and Sean, the other adult children had managed to obtain tertiary education qualifications. Zihai was 18 at the time of the interview and had failed to pass his GCSE O Levels. He was preparing to re-sit the exam as a private candidate. Kelvin had dropped out of Polytechnic after his breakdown and Sharon, who had been diagnosed with low intelligence, did not finish her vocational studies at the Institute of Technical Education (ITE) because of a breakdown. Siew Min's son, Kai Wen, was actively employed for a time after being diagnosed. But he quit his job at a bakery for reasons unknown. She wants him to go back to work, and "do something productive with his time" as she fears that being at home around his father might lead to a recurring situation of both of them fighting.

Like Siew Min, Kenneth tried getting their sons to find work. For Kenneth's son Eric who did not finish his university education due to multiple relapses, he had never managed to find work despite Kenneth's efforts to motivate him to try "even something simple" to "build up [his] confidence". Eric was adamant that people were not willing to "give him opportunities" and would refuse to even consider the thought of finding some kind of work [87].

Anna was wary of putting too much pressure on her son Sean. She admitted at a support group meeting that she didn't know how much stress she should put on Sean to find work. Sean returned to his old job after been released from hospital, but he lasted two days. He was also fired from his second job as an auditor. At his mother's urging, he applied to do volunteer work at the community centre, but after disclosing that it was his psychiatrist who had encouraged him to volunteer, he was never asked to go back. "They are afraid that they will be harmed," said Anna. Since then, Sean has gone back to his computer games and has not tried to find work again.

While Sean, Eric and Kai Wen did not feel much onus to become self-sufficient, Kelvin on the other hand showed remarkable self-expectation. He was the only other patient in the group who managed to find work. His mother, Chiew Yin, initially encouraged him to keep working, but stopped insisting after a troubling incident where Kelvin had alleged to being raped at a job interview [88].

In retrospective narratives, it is difficult to get an accurate grasp of how much pressure was placed on children to comply with their parents' expectations, as the guilt that accompanies distressing incidents (such as Kelvin's alleged rape) or the loved one's fear of social rejection might cause the parent to alter her perception of how demanding she had been at the time. Even Janine, who had high expectations that her brother would go back to work, eventually gave this up when "the thought of work makes him want to vomit". Janine believed that Sam didn't want to work because he couldn't handle the trauma of their difficult childhood. Her voice became more shrill and her face registered frustration as she described Sam's refusal to get counseling and penchant for giving "excuses" [89].

These caregivers eventually stopped expecting their loved ones to exercise initiative in job hunting. Only two patients had moderate success and it was social workers and mental health professionals who played a pivotal role in finding them jobs. However, these were in the sheltered labour market, special programmes or social enterprises supplemented by voluntary welfare organizations rather than employers on the open market. After Sean brandished a sword and screw-driver in an attempt to break his brother's room door down, Anna got on the phone to the psychiatrist, who got a medical social worker to find Sean a job. Rina made sure her son, Zihai, kept up his counseling therapy. It was through his second counselor that he was placed in a sheltered workplace at the Institute of Mental Health. At a nominal pay, he would be trained to serve customers at the juice bar. (I spoke to Rina recently, and she informed me that Zihai had stopped working because he had not been paid and the hours were too taxing.)

Melvin described his most important role as a father to be "disciplining" Sharon. Sharon had been attending a day centre with vocational rehabilitation, run by the Singapore Association of Mental Health since she was discharged. Melvin believes that the organization would be able to equip her with enough psychosocial and vocational skills for her to find a job in the service related industry, like "fast food, which she used to work before her schiz". Sharon had other ideas, and did not like day care [90].

Unlike Anna, who promises Sean money so he would do as he is told, Melvin doesn't bargain or negotiate with Sharon as he describes her as "stubborn, manipulative and unreasonable". When Sharon turned 21, he stopped beating her when she misbehaved, as "she is getting older". Being fully aware that her father has stopped raising his hand to her, Sharon has, since 2003, defaulted on work at the day centre. "There's really nothing I can do about it. Just have to think of other ways…" Melvin sighed.

Parsons and Fox (1952) regarded the family as an important sphere for regulation of its adult members. Parents provide role models for their children's occupational pursuits, and evidence shows that the occupational performance of mental patients conforms to the demands and expectations of their families, mainly through pressure from parents that patients go to work within months of their hospital release and the insistence that they live up to these expectations (Simmons and Freeman, 1959; Freeman, 1961). Numerous researchers have shown that the number of times a patient has been hospitalized and the lengths of hospitalization are inversely related to his probability of finding work and being occupationally stable (Freeman and Simmons, 1963; Strauss and Carpenter, 1974). Simmons' work on eight men with different histories of psychosis and hospitalizations show that illness alone does not determine one's occupational career. His case studies showed that the social world of family, neighbours, employers and colleagues pose contingencies to a patient's fate as a worker, where early and later socialization as well as familial expectations and support are significant predictors of outcome (1965). Early socialization into the world of work had significant bearing in the mental patients' ability to successfully enter the labour market and stay employed, but he added that in individual cases, the element of family support and the patient's self-expectations have been missed in the surveys. Patients whose families had high expectations that they should work, but failed to provide help or recognize their abilities did not fare well.

In this study, parent caregivers with high expectations eventually modified these demands when their loved ones experienced hardship in the course of finding jobs and staying employed. In fact, the hopes of "being independent" by means of active employment on the labour market had severely shrunk for the caregivers with sons whose prognosis had not improved in the posthospital period. In addition, the perceived discrimination of the country's disclosure laws coupled with the widespread social stigma attached to mental patients became more insurmountable to the patients than staying stable long enough to keep a job. Olshansky and associates (1960) found that three quarters of their sample of former mental patients concealed their patient status out of prudence when searching for jobs and about one fifth obtained jobs in spite of their disclosure.

4.3 Variations of Coping

4.3.1 Role obligations and the provision of care

The caregivers who were parents assumed much more responsibility for the long-term financial care of their loved ones than caregivers who were siblings. They all talked about the inevitable day when their children would have to do without them, the greatest obstacle to their children's survival being their financial well-being after their deaths. This was of course a problem that was inimitable for the husbands too, being the sole breadwinners. Jack and All the parents, like the husbands, talked about how they had made plans to leave their loved ones enough money to get on with life in the event of their deaths. The issue of financial resources was more worrying for the older caregivers, whose spouses or themselves were nearing retirement and would not have incomes. Ronald and Jack left their jobs before retirement age in order to devote full time care to their wives. Chiew Yin had made plans with her husband to purchase a property for Kelvin once he turned 35 and qualified for a public housing apartment. In a similar move to provide some kind of long term financial security for his brother, James had transferred ownership of his share of the family home to Henry before moving out himself. Kenneth and Jack had their loved ones transferred as patients to the state hospital in order to reduce the hefty cost of seeing a private psychiatrist. The other sibling caregivers, Janine and Grace, regarded it their responsibility to provide financially as well. It is possible that due to the narrower age gaps between siblings, these caregivers were not as burdened by their mortality than the older caregivers.

The parents did not think that their other children might be suitable substitute caregivers when they passed away. This was particularly true for Chiew Yin and Anna, who believed that their sons did not get along with their siblings. Melvin showed the most adamancy against Sharon's reliance on her younger sister. He regarded the burden of responsibility for Sharon's care as falling squarely on himself and his wife, and as evidenced in his extended family arrangement in the previous section, had no wish to share this responsibility with other family members. In particular, Melvin did not want his younger daughter to end up with the burden of being Sharon's primary caregiver, to have "her life disturbed" as Melvin and his wife have experienced [90].

This suggests that there exists a hierarchy of obligations in giving care and support, where the social sense of duty and responsibility to an impaired family member is stronger in parents than siblings. Amongst the siblings, Janine, James and Grace, the burden of care was transferred to them only when their parents had died or had become unable to provide such care. The onus fell on them rather than their other siblings because they were the only ones without their own nuclear families.

4.3.2 Kinship Role and Patterns of coping

Simmons and Freeman's (1958) study discovered that more patients who were spouses were sent back to the hospital than patients who were children with the same levels of performance inadequacy. They also verified that more husbands than sons were more able to work steadily and participate regularly in social activities. The authors posited that the kin role of the patient, or factors within the family setting, had a direct relationship with the fate of his post-hospital experience. In a further (1959) study, the structure of the family was hypothesized as a correlation to the performance of the patient. The sons who performed poorly were often residing within families with other male actors of the same generation who were "functional equivalents to occupy or share the occupancy of roles normatively prescribed for the patient" (1959: 239).

Although this study was conducted in a different cultural setting fifty years ago, the implications of their findings are still relevant today as recent studies exploring the structure of kinship ties have affirmed the impact that family role identities have on sick role behaviour. Horwitz and his colleagues (1992) found parent caregivers to give more aid and to be more involved in the care of a mentally ill adult child than his siblings. The siblings who were less involved tended to have more role commitments (employment, children, spouse and in-laws). Seng (2005) discovered that Singaporean mothers as caregivers tended to be more indulgent, self-sacrificing and had “greater tolerance” compared to the spouses and sibling caregivers. Cook has observed that mothers’ role as caregiver places them in a “double-bind” (Cook 1988: 48), as they are primarily caring for children who have failed to meet normatively defined developmental imperatives such as marriage, getting employed and moving away from the family of orientation. Role identities remain in place, shaping the dynamics of mutual exchange within the family of a mental patient.

In this study, female parent caregivers chose to accommodate their children’s symptoms, and in many instances used other strategies of managing crises and acute symptoms rather than hospitalizing their sons. The mothers described themselves as the ones juggling multiple roles in the family, the ones who made decisions regarding their sons’ health and the only one involved in providing care in the three areas of achieving normality. Comparatively, the husband caregivers who reported the same kind of role involvement used both accommodation and hospitalization strategies, although hospitalization was used more frequently in the second half of their wives’ illness trajectory. There was more use of empathy in the mothers’ strategies – coaxing, bribery and encouragement. Co-operation with psychiatrists and other mental health workers was a social support resource that was used by every caregiver. Male caregivers’ strategies were more problem-focused, using reasoning, negotiation and coercion to get compliance. This pattern of coping was also found in the sibling caregivers.

4.3.2 Social Support

Seng (2005), in a local study of caregivers' burden found evidence of social support from family networks. After release from hospital, the wife's family of origin stepped in to care for her, namely the mother, hence relieving the husband of domestic role responsibilities. This kind of triadic family organization was not found in any of the three spouse-dyad cases I studied, either in the pre-hospitalization period or after. In fact, the maternal figure was absent in two cases (the first, due to death and the second, geographical separation) and in all three cases, the wife's family of origin is best described as uninvolved in the nuclear family arrangement. The husbands received the least instrumental support in coping tasks from their family networks. Jack, however, did have friends who rallied to help when his wife was hospitalized the last two times before the interview. Rina and Grace reported receiving the most instrumental help from family members, while the rest of the parents Kenneth, Anna, Siew Min, Melvin and Chiew Yin received informal support from their relatives. The men among them said they exchanged information and were advised by relatives or siblings, while the women described themselves as "confiding" in their family in addition to advice and information sharing. The most valuable source of information support reported by all the caregivers was their support group workshop as well as mental health professionals they had some into contact with at one point or another along their loved ones' illness trajectory.

4.4 Summary

I have explored patterns of coping in the three areas of rehabilitation. The most marked change between the two time periods the caregivers were asked to talk about was in their expectations for the patient's role performance. A scaling down of expectations in the area of work functioning was observed in the parent and sibling caregivers. However, this was met with a modification of demands made on the loved one. Siblings were more actively getting their brothers to perform at higher levels of social interaction and daily life while mothers tended to demand less from their sons. It is possible that in spite of the two fathers' higher expectations and particularly Melvin's coercive strategies, their wives might have made fewer demands on the patient. A major limitation of this study was the omission of the spouses of parent caregivers whose role involvement might have depicted a more complete picture of coping. The obligation that a parent feels toward bringing up a child could explain why the parents more than the siblings assumed total responsibility for the care of the patient. A hierarchy of obligations is evident from the reluctance of caregivers to name close relatives they can rely on for instrumental support. It also determines which kin (among siblings) should provide care in the absence of a parent, as all three sibling caregivers were single, hence having fewer number of roles (spouse and parent) compared to their married siblings.

Finally, the social expectation that "healthy" individuals should be economically productive creates the conditions of stress and probable relapse for patients who try to live up to these expectations. In Singapore, the potential worker faces the threat of sanction if he fails to disclose having a mental illness to his employer, but rejection is almost always absolute if he does. I argue that the view of health-as-productivity is paradoxical to a schizophrenic's view of health as the absence of illness-triggering stressors. The patients who were doing some form of work at the time of the interview were doing so either in vocational rehabilitation or in sheltered labour markets. Consequently, the schizophrenic's inability to be a productive member of society in terms of the capitalist work ethic while he or she is “well” has implications for society’s values about health and the legitimacy of mental illness.

CHAPTER FIVE

CONCLUSION

I demonstrated in Chapter Two how individuals who had no prior knowledge or experience of mental illness in their family responded to the first signs of abnormality in their loved ones. I argued that different illness meanings – the meaning given to the experience of illness and disorder – described how caregivers labeled abnormal behaviour and explained their decision to seek medical care and what kind of care was chosen. Caregivers' responses to their loved ones' diagnosis of schizophrenia also evinces their values about health and mental illness. The pragmatic use of different illness meanings as strategies for making sense of and managing the burden of a mental patient's illness illustrates the limitations of therapeutic efficacy from the biomedical framework.

Chapter Three dealt with some of the most pertinent issues related to the diagnostic and treatment process. The way caregivers received and evaluated explanations from psychiatrists affected subsequent issues of compliance and evaluation of psychiatric treatment. For instance, self-regulation strategies give a more holistic view of treatment compliance, and supports Kleinman's assertion that the most central values in healthcare do not operate within the confines of the professional medical institutions, but rather the general cultural milieu (Kleinman, 1978b). The case studies have shown that in a pluralistic medical setting such as Singapore where alternative systems of healing coexist, the small number of cases I have studied shows us that the caregivers perceived and defined social reality in different ways which provides meaning for the illness experience and strategies for coping through the blending of health values (needs, expectations, treatment choices and evaluations of therapeutic success). Varying patterns of cultural norms, beliefs and values will give rise to varying patterns of dilemmatic concerns: when to act, what choice of action to take, whether an action is justified.

In Chapter Four where I explored the everyday care of a schizophrenia patient, the caregivers were subjected to a set of structural arrangements and value orientations that influence how they meet the needs of a loved one, how they interact with him, responds to others in and outside the family and takes efforts to maintain a semblance of normalcy and balance. In some of the cases, mental illness jeopardized a patient or the family's moral stance in interpersonal exchanges and accordingly, coping also denotes the management of perceived stigma which could deter or support the patient's social functioning. The management of potential stigma from employers was clearly a pertinent concern in negotiating the legal framework that requires that job-seekers disclose their history of mental illness in job applications and employers' reluctance to hire individuals with a mental illness. Some patients eschewed medication to avoid the side effects which would either prevent them from carrying out their social and occupational functions or draw potentially stigmatizing attention to themselves. Caregivers were hard-pressed to encourage their loved ones to avoid stressors that inevitably accompany efforts to reintegrate into the world of work. However, societal values about health presuppose that a "healthy person" must fulfill obligations of productivity and self sufficiency because of the normative expectation that he participates in work and social life. The parent and sibling caregivers who subscribed to this discourse discovered that attempts to do this caused a relapse of illness, and ultimately abandoned the expectation that their loved ones could return to the world of work. Hence, as Gerhardt (1989) has noted, social action involves the management of the body (patient) and the social environment. It pits the patient in an ongoing confrontation between his willingness to act and the available possibilities in a given situation.

My findings have evinced several important issues about health and illness. The first concerns the role of culture as resource for coping with the effects of mental illness in a close family member. The caregivers' varied interpretations of illness causation furnished meaning to the experience of a debilitating and chronic illness, departing from the explanatory systems of modern psychiatry, which according to Horton (1967, cited in Kleinman 1978) merely provides objective, scientific accounts of illness that are devoid of cultural meaning. In fact, I have shown that in half the cases, strategies used in coping with the most persistent and impairing symptoms stemmed from spiritual or religious cultural resources. The health care system according to Kleinman (1980) typically consists of three sectors: *professional, popular* and *folk* (alternative or non biomedical healers), which together, represent overlapping interaction settings amongst institutions, relationships, choices and decisions as well as beliefs and attitudes about health and illness. Hence, the interrelationships between a patient, his or her caregiver, lay and professional healers as well as the healthcare institutions of that community form a system which guides the activities and interactions of these components.

A second issue concerns the problem of the mental patient's identity. When a schizophrenia sufferer leaves the confines of the mental hospital and begins to recuperate at home, he is expected to return to a state of normality – or exit the “sick role” – which invariably means the return to the world of occupational and social function. While his caregiver attempts to ease his transition by adjusting expectations and demands on his performance in the home, a dilemma arises when the patient tries to re-enter the world of work as a healthy person. Not only does the patient have to respond to the demands of his psychiatrist and caregiver to adhere to a therapeutic regimen, he is subjected to the social dynamics of cultural values and social norms to be a productive member of society. A paradox arises in the performance of a “healthy role”, or achieving normality: while social pressures entreat the mental patient to fulfill his obligations of independence from his psychiatrist and family, the very attempt to become independent causes stressors that trigger his schizophrenia symptoms and a return to dependency. Being “well”, the fundamental freedom from severe illness symptoms hence require the patient’s avoidance of such stressors, and also the inability to perform a socially accepted role of being healthy. Therefore, a retreat from social life denotes a deviant identity because he is not viewed as legitimately “sick” as long as his symptoms are in remission, yet he is unable to perform the normative functions of social and occupation functions.

I have shown that in the struggle for normality outside the professional medical institutions, mental illness functions as an impairment or disability rather than a debilitating but temporary state. I argue that a mental patient’s identity is not as clearly defined and understood as that of a physically or mentally disabled person. A lack of public education and social awareness of the lived reality of a recovering mental patient reveals the tension of reintegrating into normal social life and perhaps the limits of psychiatric rehabilitation. Blaxter (1983) avers that in the modern world, health still has a moral dimension. Health can be seen in terms of will-power, self-discipline and self control insofar as illness is regarded as an "institutionalized role" that is partially and conditionally legitimized by the therapeutic professions (Parsons and Fox, 1952: 32).

I argue that "normality" has to be constantly and continuously performed not only in a specific institutional setting but in the home and the social milieu (community, work and friends). Psychosocial therapy and pharmacotherapy helps the mental patient reintegrate into mainstream society but only to a certain extent. Successful performance in the world of work and community requires him to cope with the inherent stressors that very probably made him susceptible to illness in the first place. My study highlights two problems that could be further explored in a more quantitative study: firstly, resocialization into the world of normals is a difficult and frustrating exercise for patient and caregiver alike. While successful psychiatric treatment can control the eruption of severe symptoms, recovery from schizophrenia is an intricate balance of family support, the patient's insight to his problems and managing stressors specific to each patient. The binary definition of being sick and well presents an unrealistic goal for mental patients whose recovery lies on a continuum of impairment and degrees of capabilities. Once patients leave professional institutions and their families in which they have been allowed dependency and even permissiveness, they have to struggle to fend for themselves in an often cold and unsympathetic workforce. The current stance that employers take towards workers, as well as the efforts of professional rehabilitative agencies could have great implications for this transition.

The second problem, or issue, lies in social role identities within the family. My data suggests that gender role differentiation is compatible with the recuperative efforts of mental patients to the extent that certain gender roles protect the mental patient from the stresses of reintegrating as a normal. The mentally ill wives encountered less pressure to return to productive social life as their husbands were willing to be sole providers for the family and even adamant that their wives refrained from economic work. The patients who were single (and male especially) lacked a partner who could provide such long term financial and emotional support and it was left to their parents and siblings to play this role. Parents understandably expressed anxiety about who would take over their role in their eventual death, and were unwilling to depend on relatives to provide the care that their loved one would require in the second half of their lifetime. The absence of long term social support in the extended family network of a mentally ill person highlights the burden of care that many nuclear caregiving families face, especially in a social context where the family is expected to undertake the primary responsibility for the physical well-being of its members. Unfortunately, the absence of husbands with schizophrenia in this study does not allow me to explore the impact of illness on the husband/breadwinner role and its consequences for a caregiving wife. Future research should focus on the availability and efficacy of state and community assistance towards caregivers who find themselves unable to provide the necessary care to a mentally ill loved one as well as the impact that kinship role might have on the variability of caregiving burden and coping.

In sum, the directions in which my research had taken me far surpass the original parameters of my conceptual framework. The rich data I have presented will benefit from careful analysis in future research on this topic. It is impossible to capture a complete picture of caregiving, but I hope I have managed to explain some of the most salient and nuanced issues that the silent but growing community of family caregivers live with.

APPENDIX I

RESPONDENTS' INFORMATION

Study Subjects (Respondents)					Patients		
	Name (pseudo-name)	**Age***	**Gender**	**Relation to patient**	**Name (pseudo-name)**	**Age***	**Gender**
1	Chiew Yin	62	Female	Mother	Kelvin	30	Male
2	Rina	46	Female	Mother	Zihai	18	Mae
3	Anna	50	Female	Mother	Sean	26	Male
4	Siew Min	55	Female	Mother	Kai Wen	27	Male
5	Kenneth	59	Male	Father	Eric	34	Male
6	Melvin	47	Male	Father	Sharon	23	Female
7	James	36	Male	Brother	Henry	44	Male
8	Grace	35	Female	Sister	Jeffrey	30	Male
9	Janine	36	Female	Sister Daughter	Sam Mrs Lin	32 64	Male Female
10	Ronald	56	Male	Husband	Dolores	53	Female
11	Wei Rong	52	Male	Husband	Maggie	49	Female
12	Jack	60	Male	Husband	Carina	44	Female

*Age at time of interview

APPENDIX II

CITED INTERVIEW QUOTATIONS

Chapter Two

[1] He insisted the maid was trying to harm him, that she was in collusion with people and had planted secret cameras in his room, taking nude pictures of him, and the photos were all over the world …I began to suspect he wasn't quite right, I thought maybe he "*zhong xie*" (Mandarin for "under the spell of black magic")! [Rina]

[2] My friend recommended this person who could lift curses. So I took him to the Tai Shang Lao Jing, first, who gave me some "holy/spiritual water" (fu shui) to get rid of the "curse". My husband's friend next recommended this *tang ki* (shaman), it's only open at night. So the shaman put my husband in a trance, and my husband said he saw himself in another realm, and he came across our maid. He asked the maid why she wanted to harm his son? The shaman interpreted that our maid and son…how do you say …… that since she was Indonesian, so she could've put some "du" (poisonous substance) into his food. Actually my husband doesn't believe in these spirits, but what he experienced at the shaman's…I mean, the way they [exorcised] spirits, he began to believe. And later when we witnessed the maid grinning at our son, after their quarrel, we had no choice but believe the shaman. [Rina]

[3] When that didn't work, other friends recommended Malay bomoh, and my Christian friends asked me to take him to church for prayer healing. But I said no, I wouldn't since I am Buddhist. Later my husband asked around, and a friend of his has a nephew in Malaysia with the same symptoms. He advised my husband to take him to a psychiatrist, don't bother to go *qiu shen bai fuo (praying to gods and seeking help from deities).* Those didn't work. My husband agreed as he believed his colleague's nephew was suffering from the same thing as my son. So we went immediately. That was Wednesday, about ten days after he started acting weirdly. [Rina]

[4] My younger sister told me, take [an article of] his clothing to the door….and then "call" him back, something like, I dunno what…this would call the spirit back or something lah….So I did that [Anna].

[5] At our old place, she complained that when we moved in, she saw one old lady in my house talking to her. That was 1989. A few years later, at the school [next to our flat], she saw an old lady waving at her. And another time she said there was some white ghostly thing in the house. We knew she liked ghost stories, she watched those films, so we thought it was her imagination, that she was imagining these things [Melvin].

[6] We didn't know what sickness she had in the beginning (in 1989), what she was suffering from. In 2000, we noticed she was cutting her hand, she had a lot of scratch marks on her hand and she started behaving differently: at night after 10pm she would keep going toilet you know, in out in out! She would spend as long as one hour inside…sometimes ten minutes depending on the situation. And sometimes she would talk to herself, go to the window and say, "Go away, go away! Don't come!" She said there was someone standing outside the window, asking her to "jump down", that means commit suicide! My brother-in-law is an Associate Professor at NUH, so we actually seek help from him lah. He asked his friend, a psychiatrist there, who said something was wrong, so we made an appointment to see this…Professor K___. He told us it was schizophrenia [Melvin].

[7] In 1994, early one morning IMH called to tell me [my wife] was there. The day before, she had gone to a seminar, I don't know what it was, and she was banned from entry. I guess she could have gotten into a skirmish with someone and the police got involved and that's how she wound up at IMH. At that point I believed the doctor who told me she must have been quite aggressive for the police to take her in. [Wei Rong].

[8] Based on what I knew about her bad temper, I believe she must have resisted. When she didn't return home the night before, I didn't panic or think of calling the police to make a missing persons report because her behaviour (leaving, taking off suddenly with no notice) had happened many times before. It was expected, it was not unusual. Whenever she gets angry or unhappy, she'd leave, she stayed at the YWCA before […] She does not communicate like a normal person, there is no negotiation with her. [Wei Rong]

[9] We blamed her, we pointed fingers at her, you know it was hard to look at ourselves, easier to blame her, like "you caused Mum's breakdown, caused Mum the heartache… my Mum couldn't function, she was depressed, she had some health problem, you know she would have bleeding problems. She would bleed non stop, and my relatives came over and gave her some medication, some Chinese herbs, don't know for what, but from then on my Mum's health got worse. And when her parents died, she realized that, she was really on her own, and I think she couldn't cope. She started to lose a lot of weight, she used to be quite plump you know, and one day, she was down to 30 something kilos! [Janine]

[10] It was a weekend, Saturday or something, they admitted her, but they couldn't give her a diagnosis. They put her in a Ward C, they said there was no doctor available, my Mum stayed there for 2, 3 days. But there was no proper diagnosis. And anyway we were very young at the time, still teenager…we didn't know what to do and we were so heart pain. So send her back lah, send her back. So since I was the one who admitted her in, I had to give consent to discharge her. The doctor told me this is not doing good for her, but then I thought look, they just put her there with no medication, nothing at all….[Janine]

[11] Janine: I talked to my friend, her father was depressed after the wife passed away suddenly. I asked my friend for advice, and she told me, "Yeah, I also don't want to let my father stay in hospital, because people who go hospital get worse afterwards!" So at the time, my perception of the hospital was that the most serious patients went there, and I could see my mother getting from bad to worse.
Interviewer: What about your relatives?
Janine: They scolded me, asked me how can I do such things to her? I believe they didn't want to acknowledge it, it was a shame to them lor. I hated them a lot for it then. At that time I already felt that they looked down on us, their perception of our family no good because of my mum…so they didn't want the stigma lor…

[12] Interviewer: You said you put up with your mother's condition even though you said it was quite bad for 15 years, did she seek treatment during this time
Janine: No, not at all.
Interviewer: And did you suspect that [the problem] was mental in nature?
Janine: We weren't so sure….
Interviewer: How did you come to suspect later on that it could be mental illness, was it something about her behavior?
Janine: She was not the person she used to be. She was not our mother like she used to be, she was not as caring as before, she became abusive verbally, and sometimes physically. Scold those four-letter words, Hokkien swear words. We thought: 'how can Mummy say those things about her own daughters?' I'm your girl y'know, how can you say that I am 'smelly'. But I think she realized she was not right already, that she couldn't help it. Shout and shout…She would hit us sometimes, she had insomnia and disturb us at night. Didn't shower And she cannot sleep, and middle of night she can wake you up, and stand beside you in the middle of the night and start all her nonsense, and nag, nag, nag, nag, nag lah, saying somebody's disturbing her lah. So you don't sleep well, don't eat well, cos my Mum, she couldn't cook, she couldn't function. She just lay on the bed, and would behave weirdly, talk about a lot of things…talk about something happening outside…she didn't eat properly so she had no energy also lah…can't do the housework, so the house was actually quite dirty. And we didn't have a proper meal so we actually ate those uh…non-nutritious things…
Interviewer: This was for the whole 15 years?
Janine: Yes. I remember she said once: 'Shhhh, the neighbours can hear us'. And later she started to see as well. She said once that somebody was climbing through our kitchen window and was going to harm her. And even when she wasn't acting up, all our neighbours avoided her.

[13] We wondered if she was really *siao* (Hokkien for "insane") we couldn't admit that there was something not right about our family. So there were a lot of factors…you couldn't get acceptance from your relatives, from your neighbours, your friends…that you're not normal, it's not just your mother who was not normal but your whole family was not normal… I came from a violent family. Every time you can hear us shouting. Like a shouting war. Not just my parents, my elder sister would side my father and I would side my mother, so it was like, different camps…We'd bang the door, my parents would break the furniture. [Janine]

[14] In 1989 when he carried around the knife, talking to the walls, we were all quite scared. You know you see those images of a happy family, the father with wife, maybe one boy one girl. So we had a disruptive family. It was so strange, someone walking about in the living room, I mean, who would want to sit in the living room? We ignored him at the time, you know, I just avoided him, I stayed in the hall at uni. [James]

[15] When I got home I thought he would whack me, but he didn't, just sit quietly. Next day, I approached the doctor, the senior doctor said the MO saw my brother and he talked to him already, so the MO also confirm it was schiz…so the senior doctor said ok lor. He said, can give me the medicine to apply lor. [James]

[16] The office called and [his boss] told me, "You better come quickly. Your brother is throwing away things…better bring him to see doctor." I took him to Adam Road Hospital. There and then, I suspected he had a mental problem just like my mother (first diagnosed and treated in 1994), and so when we knew it [was schizophrenia] we really had to admit that he had it lor…that he had a mental breakdown. [Janine].

[17] Janine: Before that he had started to throw things away, I noticed that he was very different two weeks ago. One night I woke to find him throwing things away, just throwing his things into the chute! my brother had self-admitted to Adam Road hospital before that for insomnia. I checked with Dr Wong and he has his record… he confirmed my brother was given the 'full treatment", he came here a few years ago…he actually got medication, oral medication. On and off, he took it. And he was given anti-psychotic medication as well. You know how I found out?
Interviewer: How?
Janine: Because as you know our house so messy, one day I was cleaning and I found under the coffee table, this packet of medication. You can see it was half taken. And then there was another packet lying somewhere else. You know why or not? Because of my mother, I can understand why he hide here hide there the medication. My mother doesn't let us take medication. So I think he must have forgotten all about it. I don't know if he stopped taking it and the reason for that.

[18] It was a shock to me, I mean, what's happening? I didn't want her to be taken away in a patrol car…Luckily the guy who came was someone I knew from my army days and he suggested I take her to IMH instead. So we called for an ambulance…I was so angry at them at the time, you know. But they didn't understand it was her breakdown happening…[Ronald]

[19] At first we thought he was just sick, we had no idea it was mental illness until we saw him hiding in the corner. Later on we found him in a corner [at home] saying someone trying to hurt him. He heard voices too. We took him back to the GP who recommended we send him to Mount E (hospital) to see a psychiatrist. [Kenneth]

[20] The doctor said, there's nothing wrong with your mother, there's nothing in her sole, I think something not right here you know (points to head). That was….1994. So the doctor told me to send her for treatment. I was so young then, and I was panicky, didn't know what to do. I was the only one with her, so I said okay lor. So I sent her to Adam Road hospital. [Janine]

[21] In Sec 4, the teacher didn't like him, cos he had a Mohawk. His grades went down. We took him to the Child Psychiatric Clinic at Institute of Health, this was a whole family affair. The psychiatrist was an old man ….and he told us, "Nothing wrong with your son, he's just being naughty." [Chiew Yin]

[22] In Poly (Polytechnic), he started being violent. Threw dining room chairs around, said the maid wanted to poison him. I was very very worried, I knew there was *really* something wrong. This article, in the Straits Times…described the symptoms of schizophrenia, and I suspected it was what he had…My husband was seeing a psychiatrist at NUH at the time for depression, and so we took him there. [Chiew Yin]

[23] I felt restricted. I didn't think of how I could do something to solve the problem…I just follow the older generation: "bring up the family, look after kids". Never knew to employ a maid, I never knew she wasn't capable, cos she never wanted any help. I tried to help as much as I could of course; you know our generation is caring about wife very much. My father's generation was like that. But the problem was getting worse, she wasn't happy. [Wei Rong]

[24] He (psychiatrist) told us it was mania, he said "this kind of illness, got no hope of recovery". I don't think it is ethical of a doctor to say such a thing. He gave us medication for it, but they didn't work. We went back to him to change medication, and got liquid ones to put in his food, but that didn't work either. In the end, Dr. Y___ told us to send him back to the Malaysian mental hospital! [Grace]

Chapter Three

[25] At the time it was a Dr. T___. He didn't say much, basically that Dolores needed to stay [in Woodbridge Hospital] for a while, take medication to recover…I knew she had a mental illness, but I didn't know it was schizophrenia or anything back then. Back then they told us that it was 'delusions of persecution, hypothemic or something, and depression. I didn't know what to do, now and then she would become difficult and depressed again, I would give her Panadol. It was only in the later years that her condition got worse and I realized it was schizophrenia. [Ronald]

[26] You know, I never really got a straight diagnosis, a clear explanation of what the problem really was. I'm not trying to find fault here. There were a few doctors. I didn't find out who exactly they were, perhaps one or two might have been from other hospitals. The MO who first saw me was with a nurse and some other people, and he said it seemed to be more like bipolar disorder. [Wei Rong]

[27] Unbearable! I never thought it would be like this. Heartbreaking, I never imagined it was mental illness, it was too sudden. I had no choice, I had to face it, can't not face it, I had to solve [the problem]. So I faced it. [Siew Min]

[28] [I felt] blank, nervous, lost. We didn't know what was this "schiz", this mental illness**.** We were shocked. Never before our family had this illness, and my younger daughter…. I worried if she would get this illness also or not. [Melvin]

[29] I didn't want to accept it at first…. Every night I cried lah, when I finally knew it was true (the schizophrenia diagnosis). It's a really horrible mental illness you know (frowns gravely). [Chiew Yin].

[30] I realised I had judged her wrongly, that it was more than just a problem with her temper. [Wei Rong]

[31] Everybody thought Dolores was being argumentative and difficult. Even myself, I couldn't understand her behaviour, she was so demanding…I didn't know it was her mental illness and that it was not her usual self. [Ronald]

[32] He was *veeeery* angry, angry with me for a *looooong* time. Angry because we brought him to IMH, we had tricked him. He was tied to the bed like a chicken, he said, and they wouldn't let him go home so he banged on the nurses' station, very violent, so he was very angry. [Anna]

[33] She (Jack's wife Carina) hates ECT, and would blame me every day when I went to visit her at the hospital. I felt very guilty, very bad, but no choice, otherwise she won't get better. [Jack]

[34] She thinks I am abandoning her every time I send her to hospital. She believes I am having an affair, and that I am leaving her. I have to visit her every day and convince her that I don't have other women. It's very hard….[Ronald]

[35] I used to think that I had something to do with it, when he was a child, he hit his head while I breastfed him! People say it isn't true! (laughs). [Siew Min]

[36] After I gave birth to Kelvin, I fell seriously ill […] I was in and out of hospital for eleven months! Kelvin was fostered out during this period, to my aunt and later my sister. (voice drops to a low, grave tone) I felt soooo guilty I couldn't care for him as a mother should, and I thought this caused his problem. I even wrote all this down to the psychiatrist you know, I felt so guilty. But he said no, this has nothing to do with his illness. [Chiew Yin]

[37] [My husband] has never cared about the children, he used to beat them, both of them when they were little. My son hates him too. When my son was fifteen,, he slapped my son over a skirmish over the television. I told him he's never given them any affection, never spent any time with them. For a boy to suffer this kind of treatment all his life, I believe he must be psychologically affected. [Rina]

[38] How I wish I can turn back the time. His father also watch TV all the time, didn't build up a close relationship. All their lives, they did their own thing, father never spend time with them, watch his own TV [….] So both are closer to me, I took care of them, I wish he would bring them out, play games. How can I do so many things? If they had been interested in outdoor activities they won't be so addicted to computer games. We told him those games no good…killing monsters…whole day long, killing, killing, killing. That's why he uses those equipment [to attack brother], those guns and knives. [Anna]

[39] How she got this, I also dunno, maybe was it because we give her pressure to force her to study, or because she can't study and we give her that kind of pressure […]Not say a lot lah, but ask her to study lah. But whatever she studied, she'll forget after the next minute. At 16 she was assigned to [a fast food restaurant]. And the branch manager there was really stressful. Everyday she scold my daughter, she would scold and shout and shout. My daughter couldn't take the pressure, she told me many times she didn't want to work anymore, she want to give up. I said, "Just started, what for you want to give up? Just continue lah." Then after she finished she said she wanted to rest for a few months. I let her rest, but after that we asked her why not you study lah, but ultimately she couldn't study so she ended up stay at home and do nothing lor. So we nagged at her lor, my wife and I nagged at her to find a job. [Melvin]

[40] When my Mum first got really depressed, a lot of things happened to the family […] My Dad was fighting with my Mum all the time, his business failed and then the loansharks coming after him […] My second sister had ran away from home, she got into some bad company and when she tried to come back, my father and brother chased her away, because she had been you know, "unfilial". So we also blamed her, we pointed fingers at her, you know it was hard to look at ourselves, easier to blame her, like "you caused Mum's breakdown, caused Mum the heartache…you messed up my life." [Janine]

[41] I think my parents… (voice lowers to a whisper) they never approved of him, that he didn't do more with his life. They had certain expectations for their son, but…. (voice trails off). [Grace]

[42] We told her lah, "If you don't take medicine, your situation will get worse, you won't be a normal person, and you'll get lock up." So I told her, "If your condition gets worse, I will send you to IMH (Institute of Mental Health), I will send you to Lee Ah Moy Old Folks' Home, where you'll be lock up over there." So she had no choice, she took lah. [Melvin]

[43] After the second relapse, he was staying in the [university] hostel, and we suspected he sometimes skipped his medication, so we told him, if you don't take your meds, you'll get this relapse. If you want to continue your studies, you need to take it. So he eventually accepted it. We told him, if you have high blood pressure or some other long term illness, these people also need to take meds also, for their whole lives. But he denies he has mental illness. He would say, "Okay lah, if you think I need to take this medication for my health then I take it lah. I still don't think I have mental illness. [Kenneth]

[44] He got very suspicious when I tried to give him the medication. So when we took him to this dermatologist at ______ Medical Center – he had acne, and is quite vain. So the doctor gave him pills for the acne. Then…I don't know if I should tell you this….. (pause) Well, I told the doctor that my son wouldn't take his medication for his schiz, "Can you tell him that you're prescribing him these [anti-psychotic] pills as vitamins?" And he agreed! (laughs ruefully). [Chiew Yin]

[45] Completely no response. I tried talking to her about this, no response. I cannot read her mind, to this day, I have no idea what she wants. What she wants, a normal person can never accept…. After discharge, she agreed to see the doctor, for less than 6 months, then the doctor was transferred somewhere else […] She refused to see the doctor after she was transferred to another doctor. I went to see the next doctor on her behalf for a few years. After each discharge from hospital, she would take the medication. But it's just that she gradually takes less and less of it, less often and also less likely to see the doctor. And then the pattern repeats. [Wei Rong]

46] My brother wouldn't go back [to the hospital], so after that throughout this period, I was the one who went to the senior doctor for consultation. Because I told this senior doctor[10] the MO saw my brother, diagnosed him as schizophrenia, I asked him, "Can you give me the medication, and I will have the responsibility to keep you informed." So every time I went back I described my brother's symptoms to him. But he also said even though the MO had seen my brother, he himself personally didn't see my brother, so cannot go on like that also lah… Medically, he said he was not supposed to do that. But he knew what he was doing of course….and he really wanted to help me. [James]

[47] After taking the Risperdal, he would go stiff, his whole body was like a zombie. And he would sweat a lot, he sweat so much that it was just trickling down his arms! I got so worried. I told Dr S____ about the problem and she just told me to try another type of medication. She said, "Here, why don't you try this other one instead?" It got better, the side effects weren't as severe, but later he got a growth on his nipple. I asked Dr S____ and she said she didn't know what it was or what caused it. I asked Dr S____ if there was medication for it, she told me to go see a GP myself. So I went downstairs to the GP and I got some cream for it, but it didn't work even after 2 weeks. Later my friend recommended the *Nutriaid* Mushroom drink. After three months of taking it, the lump was gone! I asked Dr S____, "Could it be the medication's side effect?" and she said, "Could be, could be!" I asked her if the medication could have caused the growth, and she said to ask the pharmacist. The pharmacist told me he didn't know either and to ask the psychiatrist. She says to ask him, he tells me to ask her, I mean these two people were driving me nuts! [Rina]

[48] The side effects made him duller, slowed his movements. Sometimes there are side effects, sometimes not, and Dr S____ told me to give him the anti side-effect meds whenever I thought it was necessary (makes a face). She said, "Sometimes you can give, sometimes don't give lor." even though I told her they were severe. The new medication she prescribed made him worse, and she told me to stop the morning dosage, just take the evening one. She said no need for any other medication. Anyway I read in the papers and radio about this Chinese psychotherapist, Dr Z____, he's a psychotherapist from Beijing who wrote many books on [mental illness]. I went to see him with my son. He told me my son suffered from *Dian Xing* (atypical) schizophrenia, he had to be on medication the rest of his life. Every case was different, and it would be complicated, not as simple as just "letting him be independent" as my husband believes. He told me to see if I can change a doctor for him. Or find someone who is older, more experienced. I didn't know anyone, I only know of Dr Y___ a private psychiatrist. My brother had recommended him. [Rina]

[49] It got worse in January this year. Ever since he took the Zyprexa, his symptoms got much worse. I told Dr Y____ and he agreed that that medication was not so good. When I next saw Dr S_____ and told her about it, she said, oh, sorry she was on leave. I thought, if I had waited for you, who knows what might have happened? So she asked me what I did, I told her I had gone to see Dr Y____. She told me the green

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[10] The "senior doctor" was the one whom James had spoken to at a mental health seminar prior to bringing his brother Henry to the hospital (see Chapter Three). The doctor had advised James to take Henry to hospital after hearing James' description of Henry's condition.

pills were not good for the heart. I told Dr Y___ about what she said, and he prescribed me another medication for the side effects. This was much better. [Rina]

[50] I called the [private] hospital and Dr W___ told me he will come to my house to get [Sean]. 'Cos Dr. W___ told me, "Bring him to me. I will give him ECT, quickly get him out of this chronic stage, you see at IMH, sooooo many of these chronic patients." He told me everything about ECT, he showed me cases after cases, hundred times of ECT, only thing was temporary memory loss. So I thought, okay mah, no side effects, only temporary memory loss. So he came with his team of nurses, they jabbed him and carried him to A___. They gave him ECT, Dr W____ wanted to give him 8-12 doses. So he talked to me like that lor, so I agreed, I didn't want him to become chronic what! Definitely I said yes to Dr W___. [Anna]

[51] I really regret it you know, Sean blames me for the ECT, he believes it damaged his brain….. I wish I known of the SAMH[11] earlier. Only so much later, much much later after the second discharge [from the Institute of Mental Health]…If I had known, I may not even have gone to Dr W___ for the ECT; I didn't know… [Anna]

[52] He said there was no choice if a patient refuses to see the doctor. All this time I gave her liquid medication in her food secretly and <u>adjusted the dosage myself</u>. I think she was clever enough to suspect something, cos she can sense the difference in the taste of the food. I admit, it's not a very good way lah….(shakes his head and smiles ruefully). [Wei Rong]

[53] I think the doctors believe solely in medication only. They give me the feeling like, there's no hope! (laughs) Nothing else they can do, since they are quite overworked themselves. I have spiritual beliefs. I hope that you listen with a very calm and open mind, I'm practising Falunggong. According to this [belief….] Chinese medicine, western medicine and even acupuncture cannot cure mental illness. [Wei Rong]

[54] One or two of the doctors also. I really appreciated them. They gave a lot of support. They will talk to you when you need to talk, they'll call you back, once in a while they'll call to check on you, this gives me a chance to relieve some of my stress. But I believe that medication must be paired with something else, it alone cannot help the patient. [Wei Rong]

[55] Melvin: At first I was thinking maybe something "dirty" had gone into her body lah. Cos many years ago, in my own company something like that happened before. I don't know if I believe it, it happened to another colleague, I wasn't there myself, it happened during the third shift. They said, apparently two or three guys tried to stop him [from strangling himself] but couldn't. Then this Malay guy start to talk the Koran to him and the thing "disappeared" and he woke up. So to me I thought something dirty went in [to my daughter] lah, I didn't really know what…
Interviewer: What did you do after the relapse?
Melvin: I didn't know must keep taking medicine at the time. Anyway, I thought the problem was something else, and medicine won't help her, since she got…you know, sick again. I thought it was something to do with the flat, it might be 'dirty' or something, maybe the spirit was disturbing her. People recommended that we get those type of [spirit healer] to come and take a look.
Interviewer: Can you tell me which people recommended this?
Melvin: Friends…some relatives, my mother-in-law. She said maybe it's not a problem with her, it's something about the house, dirty or what. So first we went to this Thai monk's house in Chai Chee. Somebody recommended. He said my house "dirty", he came to [perform rites to "cleanse"] the house. Then after two months, [Sharon was] still the same, so we got this Taoist….how do you call them? (pauses to think) That kind of tang…
Interviewer: Tang Ki?
Melvin: Ah yes! He came and told me that my daughter could see a lot of people sitting in the living room and they all were like very miserable like that, they were all asking her to help them.
Interviewer: How did he know this?

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[11] Singapore Association of Mental Health

Melvin: My daughter told him. So the Taoist guy said "it's your ancestors, they are hungry, nowhere to go…." Later there was another guy who went to learn some Buddhism thing in Taiwan, he came to check it out [my house], and same thing, also said my house is 'clean', only thing my furniture need to shift so that the main door face the shan-toi (spirit altar), so that whatever spirit thing that follows you home stops there, won't follow you in [to the house]. So we did some shifting, and then he said our ancestor tablets were poorly located, where they were at, the fengshui was no good. We spent a few thousand dollars on another location for the tablets. That was how we got converted to Buddhism lah.
Interviewer: What do you mean when you say "converted"? Is there something you practice?
Melvin: We pray lah, to the Guanyin. My wife prays, mainly to offer some joss-sticks.
Interviewer: Did you continue to use these methods?
Melvin: Ahh…(pauses to think) the praying to Guan Yin, yes. But now I know I also have to make her take her medicine.

[56] [The symptoms] came out again in September last year. And I knew I couldn't stop the Risperdal, because during his exams his voices got louder and more disturbing. We gave him 2 mg in the morning (0.5mg more) till after his exams and I changed it back to 1.5mg. We tried reducing the dosage after that, because of his side effects, they were serious. [Rina]

[57] He took this ball and threw it at the ceiling, shouting, "They are talking about me again!" I was so scared. He picked up the bowl and hit his head, kept hitting himself and saying he wanted to commit suicide. I was frantic. I wanted to slap him, shake him out of it, but I couldn't, I just broke down. My sister told me to calm down, she told me to keep it together for his sake. So I convinced him to take some orange juice, I put 3 tablets in. He calmed down after that. [Rina]

[58] I was so scared of SARS happening again, then she would be cut off from me again. While she was in there she was so scared! She has never been separated from me that long, I would always visit her in hospital. I took a chance and brought her home after her third ECT, even thought the MO advised me not to, he said patients would still be disoriented and confused. That night I had a tough time managing her, she kept running to the window shouting "*Kwei Meng! Kwei Meng*!" (Hokkien for "open the door") I think she still thought she was being locked up, from the SARS period, and kept wanting to run out of the house. So I had to rush her back to the hospital to continue the ECT. [Ronald]

[59] After that I was so afraid to leave Dolores in hospital I had to find a way. I thought about asking for her to have ECT as an outpatient instead. The hospital actually has that, but I was never told about it! Later on I found out that IMH discourages it…. But I decided to take the chance. It was not easy even with outpatient ECT, but there was this wonderful nurse, who told us if anything went wrong after ECT, to send her back [to IMH] right away. [Ronald]

Chapter Four

[60] One Friday evening around 10pm, she was just talking normally, reminding me about food… suddenly she acted as if someone had control over it. She moved very quickly and suddenly, went to the kitchen and picked up a chopper. She left the house, went downstairs. Wah! (chuckles) I am not someone with *dan* (Mandarin translation: bravery)! I sat down and prayed, meditated, I prayed to God. I experienced something I had never experienced before. My heart felt like a balloon filled with water, very heavy. I recited what my [Falunggong] Master taught me, immediately, strangely after I did that, I became completely tranquil. She came back up after a minute, as if everything was normal, and put back the chopper. She asked me where our son was. I said, "He went down to see what you were doing." My heart was pounding, I was thinking should I call the police. From the 8th floor I could hear the sound, against the lamp-post. The blade of the chopper had become dented. At the time, I really didn't think of calling the police nor did it occur to me if other people would. They probably didn't want to interfere. I suspect they didn't have the courage to either! [Wei Rong]

[61] I didn't know what to do. I was so lost that I called up the IMH hotline one day, this lady I will always be grateful to, she told me I could seek help by calling this Grace Ambulance. I called for the ambulance and they came, these two Indian men, hey! They had a way to deal with her! They had a way to bring her to

hospital. Whenever the police were involved, they'd tell me there's nothing they can do. Ever since then, every time this thing happens [the dismantling of cabinets] I'll call the ambulance. I have done it four to five times now. [Wei Rong]

[62] Anna: I was in the kitchen, the elder brother playing at the computer. Sean brought the cat to the brother, I dunno what happened, the cat didn't hurt the elder brother, so I am guessing he tried to shoo the cat away. There was a screw driver, so he stabbed Sean. That caused havoc. Sean became so angry, like mad you know….i mean with all that adrenaline running. So he went to the kitchen and grabbed the kitchen knife. Fortunately my husband told my elder son, "You go inside the room, lock the door!" Sean took the knife, hit the bedroom door, went to the storeroom, took the taichi sword…it's a weapon, and then the screwdriver, wanted to stab him back. The door locked, so he kicked it, banged it. You know he put on weight because of the medication. Put on 10 kg, now he is 74-75 kg. With all the anger, he was very strong. We tried to calm him down, I prayed…
Interviewer: How did you manage to calm him down?
Anna: I tried to bribe lor. In the end he calmed down. He wanted to report to police. He called the ambulance, they came, examined the wound… Police came, took down particulars, took the IC, want to go civil suit? He said, "no need, just let you know."

[63] He put on his sister's skirt, tied up his hair, he had long hair that time. And he just got angry, said "I don't like this place!" He kicked his sister. It was so frightening…he became so violent, dared to scold me some more! After that he left the house, went downstairs….I was soooo frightened you know, what if he goes and hurts somebody? My daughter, she told me to call the police….(voice lowers and leans forward) That was the time I could have done it, I didn't have the heart to do it, I didn't think it was necessary to do this sort of stuff, you know what I mean? I told my daughter, 'As a mother, I don't have the heart to do it.' At that time, calling police also didn't help, and I didn't think it was necessary for that sort of thing. I waited a few days then I called SAMH (Singapore Association for Mental Health). He didn't want to take medicine, and I didn't want him in an institution. SAMH told me to go IMH for medicine….Now I know what to do, next time, I will call for an ambulance. [Chiew Yin]

[64] I noticed he had a piece of paper under his left knee, and when I looked at it, it seemed like a suicide note. I got a shock of my life! He remained like that despite my coaxing. My husband came home later to find that he had a small knife hidden under his right knee. And he was talking nonsense, so I paged Dr F___ who called me back the next morning. He told me to change the Olanzapine dosage to 10mg at night. [Rina]

[65] My daughter and I were in the next room stapling some papers, he must have heard the sounds from the living room where he was playing on the computer. He thought we were talking about him, and so he charged into the room, completely in a rage, grabbed the ironing board and wanted to throw it at his sister. She was terrified. He said there were spy cams again, watching him. His voices were telling him that his father and mother were lying to him, that we are "jia hao xin" (hypocrites) and not to believe us because we were in cahoots with the voices to harm him. He went on talking about killing himself and becoming a demon (gui) to avenge the misdeeds done to him. He believed that I had given him medication to cause his illness, and he really hated me then. I didn't want to send him to IMH because in his agitated state, I didn't want to further infuriate him, he already hated me so much! I couldn't get Dr F__, because he shuts his pager at night, so I called Dr. A___, who advised me to give him the Olanzapine 10mg morning and night. He was very kind, he said it was ok, even if my son wasn't his patient, he advised me on what to do. [Rina]

[66] [Since I began] practicing Falunggong and attending the FLP (Family Link Program), I feel like I have more courage to face this, more *kuan rong* (empathic kindness) to help her. I believe that if I change my frame of mind that is, whenever difficult things happen, instead of worrying and getting upset looking for solutions I can get through it by finding peace within myself. Because of my belief in multidimensional beings, in spite of her inconsistency with medication, the situation is not as acute as before. I don't get upset so often and so easily anymore, I don't think of divorce even though she brings it up, even if she does it in front of my relatives. I won't get angry or feel embarrassed. But it doesn't mean I am fully in a tranquil state you know! (laughs) I haven't reached that state yet. But I am more confident of my ability to cope with each issue as it comes. It's just that now she gets entangled with the children…(laughs). [Wei Rong]

[67] I don't have a religion, but I am very spiritual. Not supernatural, spiritual. I will take the belief of any religion or religions. Basically it's not so much religion/spiritual that helps me. It's my friends who are older than me, in my younger days I talked to them, counselling, how to cope with problems. So when I have problems I recall lor, and practise it…and then all the various courses on counselling and coping…throughout the years…so many courses, I attended countless number of courses. My worldview has broadened through experience. I consider myself very patient, willing to give and take in terms of mindset, the way you think , make people happy rather than they serving me. [Jack]

[68] She will eat noodles, morning, afternoon, night time, which is unhealthy lah, then she will have cold drinks, buy rubbish, eat, because she's a very lazy person, she only wants to eat and sleep whole day, she can don't bathe even…my wife has to force her to bathe, and she got angry, she go in come out very fast, dunno if she got bathe or not. Sometimes she won't wash her hair for 3 days. Have to force her. In the morning, she will brush her teeth, but won't wash her face, towel is always dry one. Until I felt the towel, and I had to force her to wash her face. [Melvin]

[69] Since young we tried, no matter, Sean would sneak out, steal my husband's notebook computer, and play in bed at night. He would go to the shop nearby and play….He didn't eat until he got stomach ulcers. All his thoughts are on the game, he doesn't have time to eat. No friend, now worse, not even one friend. His brother…is not a friend lor. Just the cat lor. I have to put the food next to him, and hope he eats it, his whole mind is on the game. [Anna]

[70] He would not eat hot food, especially food that has just been microwave. I didn't know it was his delusions, he would say that the heat would damage his sperm. At first he would eat raw food, and just yesterday morning he wanted to eat the bread straight from the fridge. I told him "no, you have to heat it up first, to kill the bacteria. Even if you're afraid of the heat, you need to make sure the food is safe to consume". So he reluctantly agreed […] I have to remind him of things, like sometimes he forgets to bathe (laughs). For a year, He thinks people are spying on him, using cameras. He would wear his underwear while he showers, he is afraid people can see him naked…Now not so much, but he locks the door at night because he says people keep disturbing him. [Siew Min]

[71] [if] a problem pops up like he doesn't want to take medication, then I give him money. Also I was too generous, I gave too much….too much….(laughs) Like at Adam Rd, he was so angry…so I told him, I give you $350 a week. One year, that's $1400, I been giving that for quite some time. He goes to Potong Pasir (an aftercare centre) for counselling. [His counselor] Patricia's approach was…maybe she was too harsh on him. He didn't like being called a big baby. She asked me not to give him money, so I stopped. And he got angry with her and refused to see her anymore. So no more counselling nowadays. [Anna]

[72] I need to do work, do housework, need to become the tutor [for the kids]. I am doing everything. She does some of it, but gradually it became the minimum, get what I mean? Like, for the laundry she can put the clothes in the machine but I have to finish the job; cooking she would start out with a meal, and then she stops. One week, she does maybe 3 to 4 days, that means I have to basically act like the father, but I have to be the mother also. I have also to act like the chauffeur for the kids, the counsellor….(laughs helplessly) Many roles I had to do to bring them up to JC level. My siblings are all younger than me, they have more children than I do! *Jia jia you ben nan nian de jing* (there is a story of hardship and suffering in every family), it's almost impossible. If you have a chronic problem in the family like mental illness ….I tell you, brother, sister, they are so tired, they cannot handle. Unless they have maids, helpers, they cannot handle. [Wei Rong]

[73] Everything at home I do, very tired for me, I work, I take care of house, I take care of everything. I'm the only lady there, everything falls on me, whatever they want, also ask me. Now, Sean won't take the cat shit away, he used to do it. But it falls on me now! My husband also, everything on me. He took Sean to the doctor the last few times, but now, I have to do it. I'm very…I don't know (shakes her head, tired smile as voice trails off)…I have full time job, cooking, washing. When they were younger they take turns washing dishes but ever since the older one went and found a job, they don't do anything. So everything falls on me again. *All* on me. [Anna]

[74] [When my son was having his relapse], my husband didn't seem to care, he told me to do whatever I wanted. At that moment, I really hated him! And now, I think I still hate him. (voice very agitated) We have trouble communicating. He doesn't like my sister, he gets angry when I talk to her! Truth be told, if not for my sister and my friends, I would never have gotten through it. I was prepared to divorce him, but I stayed for the kids, I didn't want them to have a broken family. Tell me, how many women can tolerate this kind of temperament? Anyone would leave him! He has never cared about the children, he used to beat them, both of them when they were little. I do everything here. I stopped working to look after my son, just like he wanted! And he never makes any effort to take the children anywhere, only when I pester him, and even then I have to pay for the holiday with my own money! [Rina]

[75] She would steal from my coinbox, take the money to go and buy drinks, and one time I found a packet of Marlboro cigarettes in her bag. When I ask her she will bluff me lah, say she needs the money for topping up her MRT card. The one Sunday morning I smelt something very strong, she was in the toilet, and when I banged the door she ran out, and even though she flushed the toilet I saw the cigarette butt in the bowl. So I beat her up lah. (determined and certain look on face) I beat her here (points to arms). I threw away her cigarettes. I was so bloody angry. [Melvin]

[76] I already told all of them already, "don't take her in. If you take take her in that means next time you don't take her out lah". That means she will stay there, I don't want to take her back. So they don't dare to take her in. [Melvin]

[77] When she is near to a relapse, like going to relapse, she would refuse to go to the centre. She will say people force her to work, force her do this do that. Then after staying home for a few weeks, she will complain that she's bored, she wants to go out, asks for $5. My wife won't give her. And she will get angry lah, she'll go to my coin box and take, steal. So I noticed that you know…she was stealing from me, and I told her: "I give you two choices: either u go back to the Oasis Centre or I take you to the police station. You go lock up, all of us will be happy." Then finally, because of that she will go in. Same thing, ten something [a.m.] she will come back, and I get fed up, I take back the MRT card. And when I do that she will cry lor! She will start crying, banging the door, throw temper. I had no choice, every time I take away her MRT card, her handphone, she will cry, scream, disturb us all night, come in and kneel down…say "*Tolong lah"* (please), even when I slapped her she will still say *"Tolong*! I want the handphone." 'Cos I realize ….that if she is scared of no one, she will be the queen you see, then she will control everyone and we will not be able to control her. She must be afraid of somebody, then …you know she will listen. Now I also notice, when she starts growing up, I will not be able to control her in 5 years… by then I'll be old, she'll be big, I'll have problems controlling her. [Melvin]

[77] With this kind of patient, you have to have some kind of routine, a fixed time to give them money, then he will regulate his use himself. Now he's very consistent, he will ask me every week. Now I say, I transfer you the money thru ATM. He can reason, so I give him the freedom to manage his own house, I suggested that he rent a room out. Otherwise when I have not enough money to give him how is he going to survive? He accepted our proposal lor. So without discrimination but a normal relationship, that means we don't despise [the mentally ill] but we give chance, as long as their demands are reasonable, you know like sometimes it's not reasonable: why must I always give you $120? I can always challenge you to work….But now I understand they have a limitation, unless the job given to them is free and easy. He even asked me to help him find a job, one that he can work for 15 days and then take a rest. He knows his limitation, he knows that probably 15 days of a month he is functional, the other 15 no, because of the medication. [James]

[78] My brother can take care of himself. 'Cos he knows I take care of Mum. He goes to IMH now every 3 months instead of 2 months. I wrote a letter to request, cos I am the caregiver *mah*. So he can go himself now. And I train him to do some housework *lor*. Laundry, buy rice, groceries. Teach him *lor*, train and train….I give him pocket money, as incentive! I'll make sure he takes care of the house. He mops the floor, does the gardening, boils the water, wash the toilet. I'd say, 'hey, no more rice already" and I'll give him money, just ask him to buy rice, buy vitamins, groceries, anything….(grins) Sometimes I buy things for him lor. Like jogging shoes, now he goes jogging every week. [Janine]

[79] On a bad day, both of them….they will just LAZE throughout the day. Won't bother to do anything. Talking to the wall *lor*.. My Mum says, "I'm not lazy", but I make her do some housework. Like, I break it down for her, I'll prepare the menu for her, like I'll prepare the vegetables, the meat, and she will do the cooking. It builds up her confidence. Like, I make everything easy for her. [Janine]

[80] Recently ever since he went to C____ church, where there is this healer, and I asked him if he sees these things anymore, he says no. Our mind is very complex, besides medicine, spiritual healing in terms of your discipline in life, or hobbies or exercise…all this will help *lor*. I try to use creative ideas…like invite him for midnight supper, going to Church, he will be very clean (cos there are ladies there), he will spend one hour getting himself ready. So I see this as a positive sign. He is also very conscious of himself, he keeps telling me not to tell his cell-group people about his illness. Because of the medication they can't work regularly, and they are also conscious of how people look at them. They are sensitive about how people think of them, look at them. So they need human relationships, they can't be alone all the time, even normal people. I stay out of his cell-group, now I leave him alone. In the past when I tried to be helpful, I organized programs for him, activities with church people, I found there was no positive results. He would ask me if I tell my friends about my brother. So I tell him I don't know his cell group people, to make him more comfortable. So my conclusion is that he should feel positive about himself. [James]

[81] When all your friends know about it, it's easy to tell them whenever she is sick. At first, we didn't tell anyone, we thought people wouldn't understand. But later on, when more friends knew, *wah,* they came and support her each time [she relapses]. They would come to the hospital to visit her, and even come to the house to help with the cooking. After that, it was much easier every time she had a relapse because we could just come out and say it, it saves us a lot of trouble explaining to people why we can't attend gatherings and things. [Jack]

[82] I have a really good friend who's also my colleague. She is really good with my son and visits often. Her brother is in SHATEC and Zihai is interested in studying hospitality there, so she talks to him a lot, tells him about it and encourages him to try. And the neighbour at the opposite block, the one who has an old Jack Russell? That's Lucky's (the dog) friend. I'll take Lucky there every night to play with the dog and ask Zihai to come along. The old man is very nice, he's humourous and has a way of making my son laugh. After a while, he opened up more, although he doesn't say much, he comes along for the visits anyway. [Rina]

[83] This social worker was VERY helpful! (beams) She told me, why not let your Mum go to day care? If she goes back to the community it would be better for her recovery. So we negotiate with her *lor,* we said if she wanted to go home, she had to go day care centre. So she agreed. And the people there, at the Lions Befrienders, were very nice. They monitor her eating, make sure she has meals, cos meals are provided so she eats well there. And my Mum just does what she likes, she likes to draw. I think they pity her, so they actually bought her a box of colouring pencils, let her draw *leh*! They encouraged her a lot, to communicate with other people. So they would slowly draw her out *lor.* [Janine]

[84] Anna: When Sean was first discharged from hospital, I was afraid to leave him at home, so I brought him to work. The secretaries they didn't like it, they asked, why didn't I send him to IMH? Second time I brought him, he was suicidal and depressed. They made a lot of noise. They were not supportive. The bosses, everybody. Only one, that one working in the bookstore, so I let him stay with her for one or two months. [Anna]
Interviewer: Did you tell anyone from your social circle?
Anna: Yes, some of them at church. At this church, someone's daughter was very friendly to him, but somehow she found out, and asked him if he was hospitalised before. So after that she also changed, didn't want to talk to him anymore. After that whenever he went to church, he would be ignored, no one talk to him, and he didn't want to go anymore. Until now still. (Pauses and sighs) Nothing I can do, I cannot make people accept him. They don't accept him.

[85] Because of this family problem, I don't quite socialise with my neighbours and friends. I won't invite them to my house because I've no time to entertain, too tired. And they seem to know that there is

something wrong, that there's something "abnormal", but they just didn't know what. They don't have this knowledge of the problem. Singaporeans are very busy and tired, no time or extra energy to listen to you or help you. I'm sure Singaporeans are really willing to help, they go church to volunteer or things like that, but that is different thing altogether. Especially a long-term problem, people may not be interested in helping. [Wei Rong]

[86] When Dolores got hysterical that night, banging on the windows and shouting, I knew I had to get her to hospital. Those bloody neighbours would start to gossip again, who knows what were going to say about her. [Ronald]

[87] He says other people are not giving him opportunities to study, to work, so it's not because of him. He says the meds make him drowsy, so he has no energy. We try to explain to him for 20 years already… We cannot discuss work with him. Whenever we tell him, why don't you try…you know this kind of work, even something simple, it doesn't matter, build up your confidence. You can't get through to him on this one, he will flare up. He will say people don't give him opportunities, he'll get very angry. It's my biggest worry. [Kenneth]

[88] Chiew Yin: He tried all kinds [of jobs] even security guard. He told me once, "Mummy, if I could, I prefer to get cancer…at least I can still work." He tried a few times [to stay on the job], but because of the stress, he couldn't take it. But he still went to search. Then he went for a security guard job. The interviewer raped him!
Interviewer: How do you know this?
Chiew Yin: He told his psychiatrist. He wanted a blood test, for HIV. So the whole family went down [for the test] and the doctor told me what Kelvin told him. Luckily the test was negative. He refuses to talk to me about it to this day. So now I don't force him to get a job or anything like that. No point.

[89] The thought of work makes him want to vomit. He can't even take a cab to work in the morning. Sometimes he would go work for my friend, my friend's a florist, my friend is very understanding. When my brother didn't want to go work, when he couldn't wake up in the morning, he would just tell her "Auntie, I won't be coming in to work today". He always likes to give excuses. Like, doesn't want to go for counseling. Because he was traumatized by the past, I mean, we were all traumatized, but we girls, we managed to pull out of it and lead a normal life. He can't even be bothered, he can't be bothered at all. You know, like when he is frustrated, he can't seem to handle it. Actually my brother never could hold down a job you know… He was a regular in the Army, as a clerk, he didn't even complete the 5 or 6 years, he couldn't take it. He told me, partly because it was the family. [Janine]

[90] If one day, me and my wife were to pass away, then leaving my younger daughter, and if the elder daughter still behaves like that ah….then maybe everyday she will go to her house and disturb her, ask for money, call her everyday, this and that….so it's quite irritating. I try to make her more independent, find a job, get her to go to the centre. At least when one day when I am no more, my wife is no more, then at least the centre can still help her. But I'm afraid if she doesn't go there regularly, then she might lose her place, no one will be able to help her. My younger daughter will have her own family, and I don't want her to have her life disturbed…Cos me and my wife, we have had our life being disturbed, so we know it is not easy, to look after her this type of people. [Melvin]

APPENDIX III

METHODOLOGICAL ISSUES

The experience of mental illness in the family is multidimensional where no two caregivers can be said to have the "same experience". Given that the sociological focus of this study is in explaining the social dynamics of caregiving in the context of schizophrenia in the family, this involves delving into the experiences of ordinary people who found themselves grappling with extraordinary circumstances. Such an undertaking necessitates the use of multiple methods in qualitative research using a combination of empirical materials, field study and conscientious data analysis.

According to Denzin and Lincoln (1998:3) "qualitative research is multi-method in focus involving an interpretive, naturalistic approach to its subject matter". They are essentially urging the researcher to make sense of phenomena in terms of the meanings that actors attach to them, and to do this in their natural settings as far as possible. Therefore, my study is based on primary data gathered from six months of intensive fieldwork comprising participant observation in closed-door support group meetings and subsequently six more months of in-depth narrative interviews.

The data required for meeting the research objectives involve the ascertaining of attitudes and beliefs, perceptions and behaviour. These are conditions of responding and coping with stressor events (Boss, 1988) within a family unit, or situations that require the construction of symbolic reality in order to respond in kind to the stressor. However, because it is virtually impossible to be physically present in the natural setting of the family unit, i.e. the home, nor is it methodologically apt to observe actual interactions unfolding *in situ* due to the Hawthorne effect, the support group is an arena where experiences and feelings can be shared as openly and honestly as possible. Given the highly sensitive nature of living amidst mental illness and the intense privacy some caregivers prefer to keep in respect to this issue, a researcher has to first and foremost break the barrier of mistrust and fear that many caregivers and patients feel toward "outsiders". By joining the Singapore Association of Mental Health's (SAMH) Caregivers Support Group (CSG) as a volunteer, I was able to build a significant amount of rapport with members of the regular monthly meetings. I was also a co-facilitator throughout three cycles of the Family Link Program (FLP): a ten week course for caregivers with little or next to no knowledge of mental illness conducted in small, closed-door weekly meetings. Participants in my study were recruited through the CSG and the FLP.

In keeping with a flexible strategy of eliciting information from respondents, I adhered as much as possible to the principle of depth and rigour during the interview process. The next section describes and justifies the methods I employed in obtaining the required data as well as measures I took to stay within ethical boundaries to protect my respondents' privacy. The last section deals with the construction of the semi-structured interview that was used during the in-depth interview.

I) Methods of Research and Data Analysis

The study of processes involved in individuals' construction of meaning is paramount in my study, which takes a symbolic interactionist perspective to coping behaviour. The qualitative approach has been used to study the social significance attached to everyday symbols, behaviour and artefacts (Stern, 1994), and the way in which talk and actions occurring in particular contexts are constrained by, but also produce, the implicit understanding of reality shared by co-participants in the interaction (Feldman, 1995; Holstein and Gubrium, 1994). Uta Gerhardt (1990) noted that qualitative research methods are necessary to understand the subtleties and personal meanings in the management of chronic illness and Peter Conrad (1990) concurred that the subjective and changing aspects of illness require a rigorous and reflexive approach to qualitative sociological research.

I employed a combination of qualitative research methods in the gathering and analysis of primary data. I used a narrative interview as my main data collection tool, supplemented by observations and fieldnote-taking in small groups. The twelve caregivers who were eventually selected to be interviewed formed my collective case study (Stake, 2005).

Participant observation was crucial not only to designing an interview schedule with operationally viable measures, but more importantly to establishing primary contact with a community of caregivers. In the first six months of small group participant observation, my goals were to (a) establish rapport with potential participants and motivate them to be part of my study; (b) select a sample of respondents using specified inclusion criteria (discussed in Chapter One); and (c) get a feel for the nature of problems that caregivers encountered so that I could have a better operational measure of the "stressor events" that potential caregivers faced.

Participant observation as a tool involves an immersion into the actor's social world (Denzin and Lincoln, 1998) and requires a self-reflexive attitude on the part of the researcher towards data as well as the recognition of her potential influence on such factors as the location of the field setting, the sensitivity of the topic, power relations within the field and the nature of social interaction between the researcher and the researched (Brewer, 2000: 127). Positioning myself as a researcher entering a closed community implied the danger of partisanship. Katz and Kahn (1966) state that it is unwise to come in as an ally of individuals who have a special interest to exploit the researcher and who may see the research as a means to their ends. An alliance of this sort is not ethical as cooperation lent to the partisan researcher may result in undue influence upon the research objectives (1966:88). Sampling presented two problems in this regard: the first being that I had to enter the field in the common interests of all parties and also make my findings available to all groups and individuals. This problem relates to the second issue of disclosing the objectives of my study without compromising the results.

To circumvent these potential pitfalls, I sought to establish contact with the group in question through a legitimate channel by becoming a volunteer with a community mental health organization. I chose a well-established voluntary welfare organization, the Singapore Association of Mental Health (SAMH) which is financed by the National Council of Social Services. I was given permission by the Director of the SAMH to conduct my research in the capacity of a volunteer facilitator. Apart from support group activities, I was concurrently volunteering at the Drop-In Centre for mental patients who live in the community. At no time was I playing the role of a covert researcher, in the guise of being "one of them". Being amongst the mentally ill gave me an entirely different perspective of those who live with mental illness in their family. I was mentally and emotionally more equipped to converse with the caregivers and to understand their emotions having interacted and socialized at length with the members, who were sufferers of schizophrenia, bipolar disorder and depression. After I was accepted into each new group of caregivers who participated in the FLP, I presented an explicit but general statement of my research topic without giving away any variables that were crucial to the study's hypotheses.

The issue of respondent motivation was helped through my regular participation in the FLP meetings in the dual capacity of a *professional* (I was regarded by the members as having some kind of mental health expertise in spite of being merely a research student) and to a certain extent a fellow *member* of the group. Kahn and Cannell (1957) believe that individuals will be motivated to volunteer information if they desire to influence the person to whom the communication is addressed and/or a personal relationship between him and the interviewer offers direct gratification or catharsis if he revealed his experiences. The presence of such motivation helps the interviewer if the participant perceives the former as being receptive and empathic to him. The advantage bears resemblance to Weber's notion of *verstehan* (1949), or being capable of empathic understanding and being completely tolerant of the respondent's point of view. In fact, more than a few respondents expressed hope that my findings would have an impact on policy-makers whom they felt had hitherto done little to help caregivers and patients in terms of societal acceptance and tolerance of ex-mental patients. Although I was sometimes regarded as a confidant on the one hand, and an advocate on the other, this doesn't imply that I was seen as "similar". I would add that at times I felt I stuck out rather obtrusively being the only person in the group without a mentally ill relative. However, conscientious preparation of the weekly FLP lessons coupled with my own research on schizophrenia held me in good stead with most of the members and I was able to approach and convince potential respondents to grant me a private interview with relative ease.

A good deal of primary data – background information such as patient biographies, descriptions of severe crises and daily hassles, emotions, categories and patterns – was conveyed through the group discussions and informal talk. Participant observation allowed me insight into the social realities as experienced and understood by the caregivers. The field notes I took at these sessions were invaluable when it was time to design the questionnaire for in-depth interviews as I was able to select key issues and themes to focus on during the actual interview. From the onset of his loved one's illness, a caregiver's experience of coping requires almost total involvement for some, and limited involvement in others. Knowing what to look for as a researcher, be it in the particular or the mundane, everyday activities is akin to having a compass to orientate oneself to a vast canvas of complex happenings, connections and practices. Familiarity with my interviewees and becoming a trusted member of this “inner circle” further put members at ease that they could speak to me without fear that I was a government official or that their identities would be divulged. Initially, many were skeptical of the “benefit” of my research and were concerned about how I would safeguard their confidentiality. However, quite a few were willing to forsake the use of pseudonyms in place of their real names by the time I started the actual interview with them.

Twelve respondents were selected throughout the six month period of participant observations to participate in in-depth interviews, which were later analysed using the case study method. Stake (2005:446) describes the collective case study as a joint study of a number of cases mainly to provide insight into a phenomenon, population or general condition. He states that coherence and sequence are found in every case, which is likened to a system of bounded relationships and patterned activities. In selecting cases for study, they are expected to represent a larger collection of cases. However, representativeness and generalizability is not a priority in the case study analysis, for a qualitative researcher orientates to seek what is natural in settings, in expressions of value and describe the sequence and coincidence of events, revealing experiential happenings of many kinds (Lincoln and Guba, 2000). Hence, a case study is designed to develop what is perceived to be the case’s own issues, contexts, interpretations, in other words, its “thick description” (Geertz, 1973). There is however, value in this methodological approach, because case research offers an extension of experience (Stake, 2005: 460). The methods of qualitative case study, Stake argues, are largely the methods of disciplining personal and particularized experience so that from each individual case, existing theory is refined and help establish the limits of generalizability.

Sampling and case selection presented a challenge because of the limited sample population from which I could draw respondents. Working within a six month time frame, I had access to only three cohorts of approximately twenty to twenty-five new members at the FLP meetings (each cycle of FLP meetings lasting ten weeks, with a three week break between cycles). Acknowledging a large population of hypothetical cases of schizophrenia caregivers and a small subpopulation of accessible cases, I drew a purposive sample and selected respondents to be cases based on a typology of case attributes. This was the kinship relation between a caregiver and his loved one. In Chapter One, I explained the importance of studying three kinship dyads as background variables of coping – spousal, sibling and parent-child relationships. However, Stake cautioned that even within cases there exist embedded cases, or “cases within the case” (2005: 451). In the course of selecting my cases, I realized that gender was the case within the case in each kinship dyad, and worse, I was unable to find a similar number of wives to match the husband caregivers, in fact I found not a single female caregiver whose husband suffered from schizophrenia. Yet Stake avers that selection by sampling of attributes should not rank high as a priority because although balance and variety are important, he feels one should select the case from which one can learn the most (2005:451). This could be the case that is most accessible or one from which I can spend the most time with.

Inclusion criteria was based on a loved one having a medical diagnosis of schizophrenia, and being in a spousal, sibling or parent-child relationship with the caregiver. I selected a total of twelve caregivers: three husbands, three siblings (two female, one male) where one of them is also a caregiver for her mother, and six parents (four mothers and two fathers).

The narrative interview is a highly useful instrument for collecting data pertaining to past experiences, current perceptions and future behaviour, data that is virtually unobtainable by other means to the accuracy and validity of interview methods. To determine how individuals appraise a stressor event such as a nervous breakdown or a suicide attempt by the afflicted member requires knowledge that is locked "inside the individual" and which only he or she is capable of communicating (Kahn and Cannell, 1957). Miles and Huberman described responses to illness episodes as "making metaphors". (1994: 250). Metaphors cannot easily be quantified, and are used as a way of understanding in everyday life: "The social individual imposes a 'metaphoric measure' on the world made of collective portrayals that give objects and events a 'value' each time intertwined with symbolic structures of a certain historical or cultural era" (Lalli 1989: 106).

However, there are two critical limitations in qualitative interviewing. Firstly, the respondent's involvement in the very data he is providing presents the problem of bias. This is likely and evitable as individuals may withhold or distort facts if communicating these facts incurs risk of threat or harm to their personal ego (Cannell and Kahn, 1966). This kind of respondent bias is most often witnessed in deviant opinions and behaviour as well as in highly personal or sensitive data obtained through personal interviews. Kvale (1983) noted that descriptions of feelings and events given in an interview cannot be treated as merely a simple reflection of the interviewee's subjective experience. It is necessary to acknowledge such accounts as a joint product of both participants in the interview. Ricoeur (1991:34) also drew attention to "the fundamental distortions of communication" in the constitution of reality and suggests the need for one to distance oneself from the object of study in order to interpret it without the preconceived notions in language and imagery that we unconsciously use to represent everyday reality.

Nevertheless, employing this method serves to elucidate the subtle meanings and interconnections between social structures and behaviour. I conducted repeated cycles of interviewing to clarify, contradict or elaborate my preliminary interpretations until I had a consistent, comprehensive account of the phenomena I was striving to explain. This has been used to highlight the way in which non-medical factors influence the impact of disease and impairment on sufferers and their families who are beset by these problems (Bury, 1982; Schneider and Conrad, 1983; Charmaz, 1983; Williams, 1984; Anderson and Bury, 1988)[12]. This is similar to the "experience of illness" approach (Conrad, 1990;

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[12] Anderson and Bury (1988) highlighted the central role of *anticipated stigmatization* in motivating withdrawal from valued activities. Bury (1982), Schneider and Conrad (1983) and Williams (1984) focused on the *responses* to disruptions caused by illness and emphasized the strategies of *normalization* undertaken by patients to explain their current incapacitations or threats to their lifestyles. Charmaz (1983) discovered that the erosion of self-image was a far more fundamental form of suffering than physical pain

Kleinman, 1983) by aspiring to a penetrating yet sensitive description of the subjective experience of sufferers and their caregivers.

The second limitation is memory bias which calls into question the accuracy of provided information. A significant amount of my data rests on the interviewee's reconstruction of past events and experiences. Recall, or the act of remembering is typically reconstructed rather than simply reproductive (Bartlett 1932) and although accuracy of recall is important for survey research and testimony, Garro (2000) argues that it has limited application to the understanding of how people remember events in real-world situations. My study objective seeks to identify the cultural knowledge that caregivers used in interpreting events in the past, from the narrative they now used in interviews to talk about a past experience (see Chapter One). Garro, in her ethnographic study of illness narratives in a small ethnic community in Canada, described "cultural knowledge" as what is generally 'known' about a condition that is shared amongst most members of a community, whereas the illness narrative (what is remembered) turns cultural knowledge into "situated knowledge" – relating past individual experience to a particular event, context or illness history (2000: 72). In fact, narratives provide a window on the processes involved in relating a past experience to preexisting explanatory frameworks[13] currently available within the cultural milieu (Cain, 1991; Mathews et al., 1994). Rather than treat recall as a literal record of the past, caregivers' memories become a resource in negotiating problems in everyday life, in their strategies for interpreting current illness in their loved ones and for planning for contingencies in the future.

I made the best possible effort to represent the views of my subjects. Hence, I collected responses in two stages over a period of 6 months where a 3-month interval separates the two interviews conducted for each respondent. These interviews were then transcribed and openly coded, according to Strauss and Corbin, "taking apart an observation, a sentence, a paragraph, and giving each discrete incident, idea or event, a name, something that stands for or represents a phenomenon" (1990: 63).

A third follow-up interview was conducted on selected cases after one year where it was necessary to clarify certain responses or where additional data was required.

II) Aspects of the Questionnaire

I designed a semi-structured interview with open ended questions to elicit the pertinent issues and themes I wanted to pursue. Following the operational variables I had identified for study in my conceptual framework (see Figure 1, Chapter One), two or more questions specific to the variable helped to guide the respondent's narrative. Probes

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for patients of debilitating illness such as cardiovascular disease, lupus, cancer and multiple sclerosis. They experience suffering and loss through withdrawal from social life, feelings of isolation and being discredited as well being a burden on others.

[13] Researchers in this tradition typically use the term "explanatory framework", which I have replaced with "illness meaning" as I believe it encapsulates both explanatory paradigms of cause and interpretations of unfolding social reality.

were also used if respondents were unsure of or unable to understand the question. I allowed each respondent to speak freely, and very often, the conversation moved beyond the boundaries of the questions. This was advantageous because it allowed me to explore facets of their coping repertoires which I had not previously conceived of during the design of the interview schedule. The interview questionnaire and respondent profiles can be found in Appendices 2 and 3. The next section deals with aspects of the questionnaire design and issues pertaining to the interview process.

Language

The language of the questionnaire is in standard English, but the researcher should have the freedom to incorporate locally understood vocabulary, syntax and colloquialisms which are meaningfully understood and shared by both parties. The language of the interview will approximate the language of the respondent in order to communicate successfully to every participant without committing oversimplification.

Frame of Reference

Each question must tie into the perceptions of the respondent and be consistent with his notions of its salience vis-à-vis the topic under discussion. Bancroft and Welch (1944) described the effect of the respondent's frame of reference on his replies in their analysis of the Census Bureau's survey of people's employment status. Respondents interpreted the question: "Did you do any work for pay or profit last week?" in their own context of what constituted employment. Students considered themselves unemployed even though they engaged in part-time work; so did women who considered themselves housewives despite earning some income outside of the home. The effect of the respondents' differing frames of reference was an underestimation of the nation's unemployment rate. This factor is important to the framing of questions in my study. For example, the question "Did you seek help from friends or family about your next course of action?" implies a common frame of reference to the notion of "family" and even "friends". Here, the sequence of questions is vital to building a question to reflect a common understanding of the concept. I would offer first: "Can you tell me who you consider to be part of your immediate family circle?" followed by "Did you consult this circle of family members about your next course of action?"

What the respondent perceives as the goal of the research may be at odds with the questions he is asked. For instance, if I were to ask him about religious beliefs, he may find it irrelevant to the issue of caregiving, especially if he has no institutionalised religious affiliation. I framed this variable as a component of the research objective: "Some people regard dealing with a schizophrenic as a test on a person, perhaps akin to the will of God. I'd like to know if you have a religious belief of any kind?"

Question Sequence

Kahn and Cannell (1957) recommend a funnel sequence of questioning. He interview begins with a general open question that creates opportunities to direct the respondent towards specific details and areas. The opening question of my interview asked the respondent to talk about "how it all began". I did not establish a frame of reference at this point as I allow my respondent to speak freely about what he deems was the first time an appraisal of abnormality was made. This alloeds me to infer his frame of reference and to direct him to the other areas of inquiry which may be more sensitive or personal.

Information Level of Respondent

The wording of each question must factor into account the information level and the ability of the respondent to answer properly. The respondent will be less motivated to answer a question that produces embarrassment and resentment at being asked “expert questions” such as: “Did you know about the side effects of the anti-psychotic medication that was prescribed to so and so?” He may not possess the requisite expertise in this field and as a researcher, I should not expect him to engage in an uncomfortable self-analysis of issues that are unanalysed or unverbalized. This would include questions like “What was the state of your mood during this difficult time and why were you feeling that way?”

Socially Accepted Answers

Wanting social acceptance on the part of the respondent is one of the pitfalls of the respondent-centered interview. Certain questions might cause hesitancy on his part to answer, for example, *What was the main reason behind quitting your job?* This is especially if he were to offer a truth that either threatens his ego: *I couldn’t cope with the stress any longer* or induces guilt feelings and portrays an otherwise negative image of himself: *I had to do it because of my wife’s condition.*

Instead, question wording may overcome this problem by restating certain possibilities and using words that are not loaded or connote a negative type of motivation: “Many people in your situation find it hard to juggle work and caring for their loved one. Did you experience this difficulty when you decided to resign from your job?” Hence leading or loaded questions are avoided when require an answer that deals with motivation.

III) Ethical Issues

Qualitative research shares an intensely deep interest in the personal lives and views of respondents. Portraying the intimate circumstances and views of caregivers runs a risk of exposure and potential stigma, such as a loss of standing and self-esteem for those who prefer to guard their identity from the public, their employers or even friends. Schwandt (1993) notes that something of a contract exists between researcher and researched: a moral obligation on the part of the researcher, a disclosing and protective covenant, usually informal but unequivocal and open.

The respondents were informed during my field observations of my intentions for taking an interest in their stories. They were also free to decline participation in my research. Every respondent was asked for his or her consent (in verbal form and recorded on tape) before I commenced interviewing. I also requested that they give signed consent before beginning the interview. I gave each respondent the choice of replacing his or her real name with a pseudonym and assured everyone that only I would have access to their tape-recorded interview. To ensure that respondents' identities are not compromised in any way, all names of caregivers, their loved ones were substituted for pseudonyms. In addition, because I have disclosed my field site which was also the source of recruited participants, I omitted the names of private hospitals and also psychiatrists and healthcare professionals which might allude to the identity of the informant. A formal letter to the Director of SAMH also states that data collected from caregivers will not be used for personal reasons or publication other than the matters related to this academic thesis.

M.Soc.Sci (Research) Interview Schedule
Department of Sociology
National University of Singapore

RESPONDENT CONSENT FORM

I hereby consent to be interviewed by Ms Won Ting Ting Vivien for her research. I have been informed of the objective of her research and the nature of the interview questions and understand that any information I give will be treated with utmost confidentiality.

Name: ______________________ Signature: _________________

Contact Number: _____________

M.Soc.Sci (Research) Interview Schedule
Department of Sociology
National University of Singapore

RESPONDENT INFORMATION & ELIGIBILITY

Interviewer ________________________________

Interview #	**Date**	**Hour**	**Location**
1			
2			
3			

Respondent's Name _________________________ Use of Pseudonym: Y/N

Language of Interview: English / Mandarin/ Dialect: ______________________

Use of Interpreter: YES / NO

Permission to conduct interview & use tape recorder: YES / NO

Case Information

Sex of respondent	
Age of respondent	
Marital Status of respondent	
Relationship Link to Patient	SPOUSE/SIBLING/PARENT-CHILD
Clinical Diagnosis of Patient	
Patient is eligible	**Yes/No**
Respondent has given informed consent to the interview and to the use of tape recorder	**Yes/No**

Sociodemographic Information*

Highest education level of respondent 最高学历	
Respondent's gross personal income 个人 / 家庭终收入	
Respondent's religious affiliation 信仰宗教	
Respondent's type of housing 房屋款市	

RESPONDENT INTERVIEW

Variable : Discovery of Illness

Thank you for taking time to talk with me today. As you know, I've been present at the FLP support group sessions where I learnt a lot about mental illnesses like schizophrenia. I'm interested in learning about how you cope with P's illness and the day to day issues you face. I hope you could help me understand what you experience as a caregiver.

谢谢您今天能抽出时间跟我谈谈。我想知道当为一个病患者的家属，您怎样应负个种问题、在日常身活中所面对的个种情形。我希望您能协住我对这方面的了解。

[1] Let me begin by asking you about P's illness. Could you tell me how you discovered that he/she has schizophrenia?
让我先问您关于你____得病情。情你告诉我你起出是怎样发先他得精神分烈症？

[1a] Let's talk about this discovery that P's problem was psychiatric. What did the doctor tell you he was suffering from?
我们谈谈发现他有精神病的那一刻。医生是怎么对你接是他的病情呢？

[1b] In your mind, what did this mean?
在您的脑海中，这个新发现对你来说有什么意义？你怎么去分细呢？

[1c] Could you describe how the situation at home changed, if it did, after he was diagnosed as having ___________?
发现他得精神分烈症之后，家里的情形有所改变吗？请你形容是怎样的改变。

Role Identity

Variable: Nature of family role

[2] Let's talk about your relationship to P as a caregiver. Could you tell me, as P's husband/wife/sibling/parent, what are the things that only you specifically do for P?

请你说说，当为他的父／母亲／姐／第，有哪些事情是只有你才能为他做的？

[2a] Why is that so?

为什么呢？

Variable: Perceived importance of role

[2b] In your opinion, how important are you to P and his/her well-being, in general?

以你来看，你认为你对他的生活平安重要吗？有多重要？

Variable: Types of roles held

[2c] Before P was diagnosed, did you work or were you involved in some social or community activity?

在他的病情被诊断之前，你有作工或参预什么社交 / 邻里活动吗？

[2d] What about currently? Are you involved with something like employed work or some other activity?

现在有什么不一样吗？ /

现在跟往日（他病情被诊断之前）比较的话，在你各人的工作或家庭范围内有什么样的改变？

Variable: Perception of "normal day"

[3] Let's talk about a typical day when P is not having a relapse. In your opinion, what would be a good day versus a not-so-good / or worse day?

我们谈谈一个普通的一天。以你来看在平常时，当他没发病：你会怎么形容一个"好"日？你会怎么形容一个"不太好"日或者"很差"的一天？

[3a] So on a normal day, what would you say are "good things"?
[3b] And what would you say would be a "bad thing" that could happen?

Stressors

[4] I understand that there have been many different kinds of situations you have faced since the diagnosis. Now I'd like to talk about cases when P had a relapse.

你一定有经历过各种困难的情形。我想问你关于他发病时的情形。请你想想看曾经或最进所发病的那一次：

Variable: Type of event or situation

[4a] Can you describe what happened that day/time?

你能不能形容事情的过程？

Variable: Definition of situation

[4b] What was going through your mind?

你当时有什么感想？

Variable: Timing
[4c] When did this happen?
事情发生在什么时候？

Variable: Duration
[4d] Can you remember how long this went on for?
你记得事情得过程是多长时间？

Variable: Perception of severity
[4e] In your mind, how serious was the situation?
于你那时候得判断，事情有多严重？

Variable: Response/ Network activation
[4f] What did you do? 你采取什么行动呢？
[4g] Who was the first person you went to? 第一个人所帮助你是谁呢？

[5] Was there a situation for instance, when you were out somewhere running an errand or at work, and something had happened to P?
你有没有经历过这种问题：当你在外时，你的__便出事或跟某人在某地方偶发事故／件？

[5a] If yes, ask 4a-4g
[5b] If no, ask: is there someone always on hand to make sure P gets from place to place, or making sure he's not left alone?
你有没有信心让他独自出门，到外头去？

[6] Suppose P refuses to take his medication or even see his psychiatrist. Has this happened before?
当他不肯吃药或看医生，你会怎么去应负呢？
[6a] If yes, ask: Can you tell me what happened?
请你形容事情的过程？

[7] Can you think of any other situation that was difficult or extraordinary?
你能不能想想看还有什么不容易处理的事故吗？或者异常的行为？
[7a] If yes, ask 4a-4g

Variable: Participation or use of social network
[8] You mentioned some of the problems you had to deal with regarding P's illness. Can you tell me who you first turned to during those times?

请你说说当你须要应负各种困难的时后，你会不会找个家属 / 亲戚 / 好朋有来帮忙？

[8a] Could you tell me who you went to for advice, or just to talk about things?
你有没有曾须要和别人谈谈你的困扰，或问他们的义件？你会去问谁呢？

[8b] Could you tell me if someone had given you support or a listening ear when you were going through these problems?
当你应负这些难处时，有谁会支持你或劝导你吗？

Religious Beliefs

Variable: Beliefs about etiology and treatment
[9] Could you tell me, in your opinion, what's the best explanation for P's problem?
于你所知，什么才能最正却地解释你____患病的员因？

[9a] Is there any other explanation you can think of?
有其他的解释吗？

[9b] How do you feel about these explanations?
你对这种解释有什么看发？

Variable: Knowledge about etiology and treatment
[10] What do you personally know about P's condition?
你各人对他的病有什么认识？

[10a] What do you believe is the best way to cure or treat P?
你认为什么种治疗才是最有用的？

[10b] Besides the people you know who have helped you, have you found your own ways to cope and manage P's problem better? For example, do you try to read up on schizophrenia, or use the Internet?
处了你身边的亲人好友以外，你自己是否想出其他可以帮助你和你____的方法？

[10c] As of right now, would you know where to go or which persons to ask for help the next time P has a relapse or there is a similar stressful situation?
如果他再次发病，你会如和应负呢？

Social Networks

Variable: Network Structure

[11] Let's talk about the people you know who may be of help to you in times of crisis or stress. First, could you tell me who lives with you? *(Show R enumeration table of Household Members)**

现在我想问你关于你的家属或亲戚所演的角色：

请告诉我你家中住哪些人？

Variable: Content of network

现在我想问你关于社交圈子的内容。

[11c] How many people do you consider as your close friends?

请你说说你本身有几位亲密的朋友？

[11d] By "close", do you mean

"亲密"的意思对你来讲是。。。？

[11e] Are they colleagues or people from school or someplace else?

[11f] Suppose P had to be accompanied somewhere and there was nobody at home to take him, or perhaps you need to go away for a few days, who will you ask for help in this case?

假如有一天你忙着工作而无发走开，那你____又必须要有人陪他去某地方，你会不会要求某某人帮忙呢？

或者如果你须要出国工办，你会怎样安排他的照顾？

[12] Do you belong to any church, business, community groups or clubs?

目前你是否参加邻里 / 工作 / 社交 / 信仰之类的活动？

[12a] If so, how many are friends or people you most often socialise with? (This includes support groups and non profit organizations related to mental health)

当中有几个算是你的好朋友，或者跟你有社交 / 友善的来往？

[12b] Besides your close friends and social contacts, is there someone or some people with whom you go out and do social activities with (e.g. for a meal, shopping, a movie, sports, hobbies)?

你还会和其他人来往吗？比如：吃饭 / 购物 / 运动等

[12c] When you have a personal matter or when someone close to you worries you, is there someone you can talk to?

当你个人有些困扰或令你担心的问题是，你是否可以跟某某人诉苦吗？

[12d] If so, who would you talk to? 那个人是谁？

[12e] Before making any major decision, is there someone you would consult with before going ahead?

在你要做一个很重要的决定之前，你会不会现和某某人谈判／商量？

[12f] If so, who is that person or persons? 那个人是谁？

[13] When you are ill or feeling physically unwell, who would you turn to or what would you first do?

[13a] When someone in the family including P feels unwell (stress, physical symptoms, behaviour problems) who would you turn to first?

Variable: Social visibility of illness

[14] Is it easy for you to talk about P's mental illness freely, or do you feel you have to keep it private?

对你来说，你是否觉得容意告诉别人你____有这种病？还是你必须保持密秘？

[14a] Could you tell me if there are specific people whom you chose NOT to reveal P's condition to?

你是否会对某某人特意保守这个密秘？

[14b] Can you tell me why? 为什么呢？

Variable: Social Support

[15a] Do you see a psychiatrist regularly? (or use any other type of mental health service)

[15b] Do you have difficulty getting P to see a doctor? Could you tell me more?

看医生这方面你碰到困难吗？能不能解释原因？

[16] It is believed that seeing a psychiatrist, psychologist or counsellor offers the best chance of P's recovery. Do you agree?

你是否同义心里学家／服导人员会使你____的病情有所帮助？

[16a] Is there enough expertise (on the part of mental health professionals)

你对心里学家的专业技能／知识方面有什么看法？

[16b] Are the services expensive or affordable to you?

这些医疗服物对你来说会不会太贵？

[16c] Is it more or less easy to get there from your home?

你认为底达医院／诊疗所的路程方不方便？

[16d] Are there any other problems in regard to getting treatment or help?

在接受 / 寻求诊疗的方面，你本身还经历过哪一些困难？

[16e] Can you describe to me the best service you can think of that is needed but is not provided now?
你认为什么医疗服物是对病人最有帮住的，但目前并不存在的呢？

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