COPING WITH SCHIZOPHRENIA AMONG CHINESE FAMILIES IN TORONTO

By

Christina Wai Mei Chan

A thesis submitted to the Faculty of Graduate Studies

in partial fulfillment of the requirements for the degree of

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ABSTRACT

This thesis is the result of a qualitative study examining the coping strategies of first generation immigrant Chinese families with individuals with Schizophrenia living in the Greater Toronto Area. For the purpose of this study, the term families includes the individual suffering with the illness, plus siblings and their spouses (if any) and parents. The particular focus of the study is the identification of constructive strategies utilized by families, and their difficulties.

The methodology of this study was that of in-depth interviews with both individuals with schizophrenia and their primary family caregivers. The inclusion of both parties was considered important as under the Ontario mental health policy, greater responsibility for taking care of persons with schizophrenia may shift to themselves and their relatives. In addition, research consistently indicates that the course of the illness and the family environment are connected. Finally, Chinese have a strong family concept and it is essential to use a holistic perspective in studying their coping.

The findings of the study include the fact that the individual with the illness tends to try to utilize all of his or her resources and turns to immediate family members for additional support. The support of the family is found to be high throughout all stages of the illness from discovery to maintaining stability.

Secondly, three types of interactions are found between the individuals and their primary caregivers in the stage of maintaining stability. These are problem free interactions, burdensome/dependent interactions and conflict/tension-laden interactions. These types of interactions reflect whether the degree of involvement of the relatives meets the independence needs of the individual with the illness.

Finally, it is apparent that due to the long term and serious nature of schizophrenia, the family must turn to external resources to assist them in dealing with the illness. However, there are barriers to using external resources. The major one is the social stigma attached to mental illness.

In addition, the vulnerabilities of new immigrants, in terms of lack of knowledge of English, services, and the city make it difficult to link up to appropriate services.

The implications of this study are that work with individuals with this illness must include work with the family caregiver(s), with particular focus on assisting the relatives in reducing their involvement so as to allow the individual to have more opportunities to express their needs for independence. As well, the individuals must be encouraged to assert their independence needs. Secondly, as the family takes up great responsibility in long-term care, the government should be prepared to give more support to families to assist them in this demanding capacity.

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CHAPTER ONE

Introduction

As a community mental health worker, I have observed the struggles of mentally ill persons and their relatives in accepting and managing their mental illness. They may at times be in disagreement with one another over managing the illness and this creates tension and power conflicts within the family. I have a great interest in knowing how families with a schizophrenic member cope with this mostly chronic and episodic mental disorder from the perspectives of both the affected person and other family members. There is little research available on how persons with schizophrenia interact with their relatives in coping with the illness. Relevant literature focuses either on the perspectives of consumers or families, and the discussion of family generally excludes the person with mental illness. This study will adopt a holistic view of family that includes both perspectives. There is also limited knowledge available about strengths and capacities of families in coping with schizophrenia. The focus of my study therefore will be an examination of the family's constructive efforts to cope with schizophrenia from a dual perspective.

The Ontario government, in its mental health policy paper, Putting People First: The Reform of Mental Health Services in Ontario (1993), outlines plans to transfer hospital resources to community mental health services and to make the development of consumers' and families' initiatives one of its funding priorities (Ministry of Health Ontario, 1993a). The implication of this plan is that greater responsibility for taking care of schizophrenics may be transferred to consumers themselves and their relatives. In my work experience, it seems that these groups frequently do not have the information, skills or resources to manage the illness adequately. It is thus important to hear from the perspectives of consumers and their relatives what they have done (which represents their best efforts) and what would have given them more competence to cope with the illness. Understanding how families cope may lead to the development of new social work interventions in working with families.

The assistance of a social worker can enable families to manage schizophrenia more effectively, especially those families of ethnic minorities who are new immigrants to Canada. New immigrants need to adjust to their new environment, and some may have to do this with diminished social support. With these vulnerabilities, it may be more difficult for immigrant families to manage chronic disorders such as schizophrenia. Family stress theory proposes that the perception of a stressful event varies among different ethnic-cultural groups (Tseng & Hsu, 1991). In addition, certain coping patterns can be observed more frequently in families from particular cultural groups (Tseng & Hsu, 1991). Therefore, the study of family stress and coping is culturally sensitive and must be performed within a cultural context. However, there are very few studies on the coping of ethnic groups with mental illness.

Chinese families are chosen for my study because I have the asset of speaking the language, specially the Cantonese dialect, plus I work in the mental health field, presently in Toronto and previously in Hong Kong. Of greater importance is the fact that there is a lack of knowledge of how families (including both persons with mental illness and their relatives) cope with severe mental disorders. My study of Chinese families can help to bring into greater relief the nature of family interactions due to their strong family values. Successful completion of this study will contribute to a better understanding of familial relations and strength in managing the impact of schizophrenia on families.

My research question is how Chinese families in Toronto cope with schizophrenia. For the purposes of this study, families include the individual with the illness, plus siblings and their spouses (if any) and parents. I define Chinese families as families who are of Chinese origin and who use Chinese as the major medium in their family communication. This definition is based on Giles' view (1979) that language is the most important component of ethnic identity. This implies that the study will include Chinese from Vietnam or other parts of the world, who choose to identify more with the Chinese language than their country of embarkation. It also implies that some families who come from Hong Kong, Taiwan or China may be excluded if most members do not communicate in Chinese in their daily contacts. Relatives are narrowly defined as the parents and siblings of the individual with the illness.

A broader definition of Toronto will be used, as Chinese tend to cluster in a number of areas such as Chinatown, Scarborough and Richmond Hill. Thus, for the purposes of my study, the term "'Toronto" refers to the "Greater Toronto Area" (GTA) which includes Markham, Pickering, Mississauga, and Richmond Hill. Toronto is highlighted to delineate the possible differences with Chinese families in other areas of the world. Schizophrenia is defined according to the Diagnostic and Statistical Manual of Mental Disorders Version IV (Appendix A) in order to identify participants. Participants, however, may define their problems differently and thus use different coping tactics.

Schizophrenia is a severe mental disorder which impairs its victims and thus impacts on family relationships. Instead of viewing relatives as the cause of the illness or the major stressor that influences its course, they are now considered as active copers in an unusually demanding situation. The relative is in fact coping not with the person with disorder in the family, but the disorder itself. The family members with schizophrenia are not regarded as problems for their relatives. Instead, they are viewed as persons struggling with schizophrenia and working hard to manage the impact of their illness. This view, which distinguishes the person with schizophrenia from their illness and dysfunctional behaviours, helps with the acceptance of and adaptation to the illness for both persons with the illness and their relatives. Whether individuals with the illness and their relatives have this perspective is reviewed in this study. The dual perspectives of relatives and their members with the illness are examined in this study to illustrate their interrelation.

Individual family members may deal with the impact of the illness differently depending on their role and relationship to the member with the illness. Moreover, they are proceeding through their life cycle and have their own developmental tasks. Due to the small number of participants, it is preferable to have families that are all at the same developmental stage in this study. Families of aging parent/s with an adult schizophrenic child are chosen as the participants for this study since this type of family relationship is more common among mentally ill adults living at home (Lefley, 1987a).

Data for this study were collected through a qualitative method from December, 1995 to September, 1996. Family participants were recruited from an ethnic community mental health agency. Eight families (16 people) have been interviewed. All interviews were conducted in the Cantonese dialect.

The persons with schizophrenia are primarily in their thirties and forties. Five are male and three are female. All except two are unmarried. Six of them live at home with parents or together with siblings. Only a few have part-time jobs and most of them live on general welfare assistance or family benefits assistance. The age distribution of their parents interviewed is two in their fifties, four in their sixties and two in their seventies. None of the parents interviewed are presently working outside of the home. The financial resources of the parents range from independent and comfortable to supported by children or government allowances/assistance for seniors. All families are first generation immigrants.

This thesis is presented in eight chapters, and this chapter introduces the research focus and its objectives. Chapter Two reviews relevant literature about schizophrenia, coping, family and culture. Chapter Three describes the framework which provides a direction for this study. In Chapter Four, the methodology of this research is presented.

The findings of this study are presented in three chapters, five through seven. Chapter Five presents data indicating that there is a high degree of family support in coping with schizophrenia throughout the process, from discovery to maintaining its stability. Chapter Six looks into patterns of interaction between main caregivers and their members with schizophrenia in managing the illness at the maintaining stage. Variations of family support are explored with references to their perceptions, available family resources, and their emotions. In Chapter Seven, the importance of social support is discussed, and the barriers against families in coping with the illness are illuminated.

The last chapter contains the conclusions of this study. It presents a summary and discussion of the findings, and implications for social work.

CHAPTER TWO

Literature Review

This Chapter will review the literature on schizophrenia and family. This includes a discussion of (i) the impact of mental illness or schizophrenia on families, (ii) their coping with the illness, and (iii) the family recovery process. Finally, Chinese family and culture will be explored.

2.1 Schizophrenia

Schizophrenia occurs in all societies, with a prevalence rate of about one percent (Ministry of Health Ontario, 1993b). Presently, most researchers and clinicians agree that schizophrenia is a biopsychosocial disorder (Booth, 1995). Schizophrenia is characterized by various symptoms which can be organized into disturbances in several major areas - thought, perception and attention, motor behaviour, affect or emotion, and life functioning (Davison & Neale, 1990). The disturbances can be categorized into positive and negative symptoms. Positive symptoms consist of excesses such as hallucinations, and negative symptoms consist of behavioral and cognitive deficits.

The course of the illness varies from one patient to another, but its outcome is generally poor. About 25% of schizophrenic patients have complete remissions and about 10% remain severely psychotic, while others experience minor residual symptoms or alternate between improvement and acute psychotic lapses (Barham & Hayward, 1990). There is an enormous number of variables which affect the outcome of the illness such as: prodromal symptoms, (a prodrome is a set of new and unusual feelings, perceptions, ideas, and behaviours of which a patient gradually becomes aware over a few weeks or months), premorbid functioning (performance before the onset of illness), type of symptoms (positive symptoms and negative symptoms) and familial and sociocultural context (Booth, 1995).

In sum, this episodic and chronic illness greatly incapacitates the affected persons and poses significant stress on their families.

2.2 Changes in View of Family

In discussing the changing view of the families' role in the literature, the definition of family is one which excludes the person with the illness. Historically, families have been viewed as etiological factors of mental illness; later as stressors to the mentally ill member, affecting the course of his/her illness. The most recent view of families is as that of a "coper" to stresses induced by chronic mental illness.

Fromm-Reichmann (1948) proposed the concept of the "schizophrenogenic" mother (cited in Tompkins, 1995). This mother was cold, critical, and overprotective, and was said to produce schizophrenia in her offspring. The other prominent theory was the "double bind" developed in 1956 by Bateson and his colleagues (cited in Hatfield & Lefley, 1987). "Double bind" means expression of two messages, one of which denies the other. They proposed that the constant subjection of an individual to a double-bind situation caused the development of a schizophrenic disorder. Lidz and Lidz (1949), and Wynne and Singer (1963) introduced "communication deviance" as an agent in the etiology of schizophrenia (cited in Johnson, 1990). Their work spawned a new line of research on families of the mentally ill, using the "systems" approach (Johnson, 1990). The system-oriented theorists also attributed the onset of mental illness to the family. In their views, mental illness was a manifestation of problems in the family (Hatfield & Lefley, 1987). As a response, family therapy was conceived to help families become more functional.

Studies have shown that high levels of "expressed emotion" of relatives were associated with higher rates of relapse of schizophrenics (Hatfield & Lefley, 1987). Their work led to the formulation that family can exert a considerable influence over the course and outcome of schizophrenia. In viewing family as an important factor in managing the environment of schizophrenics, a psychoeducational model of working with families was developed. This was designed to equip families with knowledge and skills, with the goal of reducing the emotional tension in the family. This psychoeducational approach is consistent with families' needs for information and advice, though it regards families as the stressor (Bernheim, 1989).

The recent view of family has been changed from a conceptual model of pathology to one of stress, coping and adaptation. Instead of perceiving family as an etiological factor of mental illness and contributing factor in rates of relapse, there are greater concerns around the consequences of mental illness on families and how they deal with those consequences. This recent view holds a more understanding attitude towards families. This change may be a result of advocacy by family groups. They question the pathological conceptualization of families held by professionals. They argue that the high level of emotion expressed by relatives is either an inaccurate reflection of caregivers' usual level of interaction with their member with illness in the natural home environment (Biegel, Sales & Schulz, 1991) or is a stressful response towards schizophrenia. Family advocates also argue that it is "just one example of a range of environmental stressors that can trigger psychophysiological arousal and decompensation in persons with a core biological vulnerability to excessive stimulation" (Hatfield & Lefley, 1993, p.81). They advocate for professional support that matches with their needs for knowledge and skills in coping with the illness.

The changes in the view of the family have launched parallel changes in understanding persons with schizophrenia and in the model of treatment for them, as well as in the family-professional relationship. No matter what the changes in the conceptualization of family role are, persons with the illness remain in a passive role of recipients of care in this family perspective. In the view of persons with mental illness, this exclusion of their active participation cripples their functioning and recovery (Kersker, 1994).

2.3 Recognition of Patients' Perspective

While the view of family is changing, people with mental illness have also initiated change to have more control over their lives. They used to have a passive role and be recipients of care. In the 1970s, people with mental illness started to voice their discontent with the mental health system. They criticized the system as dehumanized, oppressive and paternalistic, and advocated for alternative community services such as mutual (or peer) support groups (Chamberlin, 1979).

The relationship of people with psychiatric illnesses to the mental health system has changed dramatically over the last ten years (Butterill & Paterson, 1996). There is a growing phenomenon wherein patients have organized themselves to serve their own needs and named themselves as "consumers" or "survivors" of the mental health system. They advocate for increased power in decisions affecting treatment and incarceration. They ask for support and deny the need for overzealous family protection (Kersker, 1994). In their view, it is best for them to advocate for themselves, as relatives do not always know their true concerns, and the act of advocacy in itself induces growth and recovery. They have learned to express their own needs, which may occasionally be in conflict with those of their relatives. A frequent example of this is their right as an individual adult to refuse treatment. Persons with mental illness demand to be seen as people with abilities and not merely with diagnoses, and seek to be treated as equals when relating with their relatives and professionals.

With the recent growing assertiveness of consumers, there is greater interest among professionals in learning about the subjective experiences of people with mental illness. The recent consumer-authored literature has reported that they strive for recovery and see themselves having an active role in the process. It draws attention to the role that relatives or significant others play in their recovery. However, there is almost no literature examining this relationship. Butterill and Paterson (1996) comment that the available family literature only explores the stress and adaptation of the family, and ignores the need to have reciprocal family-consumer relationships. They state:

> What the literature suggests are two different views of the problem and two different agendas for the treatment setting. These differences place the clinician in the position of being asked to see the problem from the point of view of either the family or the consumer. Depending on the extent of the polarization, the clinician may find it impossible to engage the whole system. The clinicians' dilemma becomes one of how to incorporate family and consumer perspectives into a viable framework that is enriched as well by theories of family functioning (p. 52).

To promote a change in this polarized conceptualization, Butterill and Paterson (1996) suggest a model of familial relationships. This model sees families and consumers as interacting systems which exert influence over each other. It includes the consumers' perspective of viewing them as active agents who respond to the hope held by significant others along with families' needs to adapt to the stress induced by the illness. They proposed a new concept that has never been explored in research. This study adopts this integrative approach to reflect how this shift in conceptualization works in actual family situations in their coping with schizophrenia.

2.4 Family Burden And Stresses

In order to understand how families manage mental illness, burden and stresses induced by the illness on families have to be discussed.

The actual problems of caregivers with mentally ill relatives include: time and financial strain, disruption in family relationships, periodic crisis involvement with police or emergency services, and management of undesirable behaviours (aggressive or abusive behaviours, poor personal hygiene, medication non-compliance, positive and negative symptoms of the illness, and conflict with neighbours). The psychological distress of caregivers derives from the loss of premorbid personality of the sick member, disappointment with treatment effectiveness, and worries about the sick members' inability to perform age-appropriate roles as well as their futures. Caregivers go through the emotional changes of loss, stress, exhaustion, guilt, fear, embarrassment and anger. The stigma attached to mental illness poses further stress for them. Caregivers also feel frustrated in negotiating with the intricacies of the mental health system and in interacting with mental health professionals who typically ignore caregivers' needs and exclude them from the treatment process (Birchwood & Smith, 1987; Lefley, 1989). Caregivers of psychiatric relatives frequently experience social isolation as a result of the social stigma of having mental illness in the family and of the caregiving role (Noh & Turner, 1987). With all these difficulties, it is common for caregivers to have reactional emotional disorders, somatic symptoms and impairment of social role performance (Bentelspacher et al., 1994; Johnson, 1990). These problems of caregivers are areas to be explored in my study.

Burden of relatives is considered to be related to various factors such as symptoms and functioning of the sick member, living arrangements, adequate psychiatric and social services, personal resources, and satisfactory support networks of relatives. Studies have shown that caregivers' perceived competency or sense of mastery, along with professional support, as well as the mentally ill member's own support network, is significantly related to the emotional burden on caregivers (Axelrod, et al., 1994; Crotty & Kulys, 1986; Mosca, 1992; Noh & Turner, 1987). This implies that caregivers' burdens may be reduced by helping the member with mental illness to develop his/her social network, by assisting caregivers to develop personal control or competence and by offering practical advice to the caregiver.

While the burden of caregivers with mentally ill members is well documented, there is very limited literature discussing the impact of schizophrenia on the person with the illness living in community. This limited literature tends to report that persons with the illness find it hard to concentrate, to deal with ambiguity, to handle their symptoms and medication side effects. They also have difficulty in communicating with people because of their altered perceptions and responses (Leete, 1987a). In addition, they mourn the loss of years in which they did not make a conscious effort to develop a sense of control of their lives (Leete, 1987b). Persons with mental illness struggle for their identity, and have adjustment difficulties after hospitalization and barriers to working (Lord, Schnarr & Hutchison, 1987). The impact of the illness on them is considerably different from that on their relatives, and thus leads to possible differences in response to the illness.

In the past, individuals with the illness have been seen solely as passive recipients of care by relatives and professionals. More recently, this view has changed towards that of having increased responsibility in managing their illness. Due to the recency of this shift, the literature on the subjective impact of the illness on individuals with mental disorders is quite limited. The inclusion of the perspectives of the ill member in my family study not only fill the knowledge gap, but also reflects the new conceptualization that they are persons with their own capacities interacting with their relatives to manage their illness.

2.5 Family Coping

Coping is generally regarded as any attempt made to alter the mismatch between the demands and resources of an individual or a system. Before coping strategies are undertaken, there is a process of appraisal to judge an encounter event as stressful. Lazarus and Folkman (1984) viewed that coping serves the functions of managing the problem and regulating the emotional response to the problem (cited in Marsh, 1992). Coping is determined by resources and constraints (which may limit the use of resources). Resources include health and energy, general beliefs about control, problem-solving skills, social skills, social support, and material resources. Constraints may be personal (including internalized cultural values and beliefs) or environmental (e.g. competing demands). Coping strategies can be divided into four categories: problem-oriented, emotional, cognitive and physical (Hatfield & Lefley, 1987).

In the view of Spaniol (1987), the differences between caregivers of the disabled and non-disabled lie in the frequency, chronicity and intensity of the problems they faced (cited in Hatfield & Lefley, 1987). Spaniol also commented that although there is an increasing amount of information on the burden and needs of caregivers with mentally ill relatives, little information has become available on how they currently cope with their problems.

Among the few studies, Hatfield (1979) and Lefley (1987b) reviewed that families with seriously mentally ill members found the coping strategies of seeking information on the illness and medication, learning new skills in dealing with sick members' behaviours, and soliciting support useful. Spaniol et al. (1984) reported in their survey that caregivers maintained balance in their lives, and used personal strategies such as accepting, distancing, and setting limits to take care of themselves (cited in Hatfield & Lefley, 1987). In particular, caregivers who were religious used their beliefs to sustain them in their daily lives.

A striking problem-solving strategy of relatives of the mentally ill is to form self-help and advocacy groups. In the United States, the growth and influence of the National Alliance for the Mentally Ill (NAMI) since its establishment in 1979 provides empirical evidence of the coping capacities of many families of the mentally ill (Lefley, 1990b). Members of this organization take a strong stand in rejecting the family-environment etiological theories and view that families are heavily burdened by the care of a mentally ill member. NAMI not only focuses on sharing, support and information exchange, but the group is also politically involved as a social change agent to advocate for better treatment for the mentally ill and to help shape government policy (Lefley, 1990b). As a group, NAMI has largely been formed and run by relatives. However, consumer groups prefer to advocate for themselves to assert their capacity for active participation in the management of their illness.

Similar to the scarcity of information on the impact of the illness on the sick person, there are few studies on coping with the illness from the patient's perspective. Leete (1987a) described that she tried to understand her illness, recognize her warning signs of relapse and set achievable goals. She viewed that hope was crucial to recovery, and asked for support that built on consumers' assets and respected them as persons with value. Therefore, it is important to know how the person with schizophrenia copes with the illness with the available family support.

Professionals have explored the vulnerability and resistance factors that may account for differences among individuals or families in their coping behaviour. Hatfield (1981) in an exploratory study of caregivers of relatives with mental illness found that effective copers tended to be older and better educated, and that their sick relatives tended to be older, to have been ill longer, and to be less functional (cited in Marsh, 1992). In a content analysis study, Kuipers and Bebbington (1985) found that the more caregivers are capable of managing their own feelings, the more they will be able to deal with the patient on a effective level.

Glynn and Liberman (1990) developed a stress-vulnerability-protective framework to understand factors involved in determining outcomes accruing to patients and relatives dealing with severe and chronic mental disorders. It views the experience of mental disorder as a process extending over long periods of time. The process intertwines patient and relatives in an embrace of stressful and protective factors that, combined with more enduring vulnerability factors, determines the course and outcome for the patient and relatives alike. The intermediate states that result when stressors, superimposed on vulnerability, exceed the coping and protective resources available, generate stress for both patients and relatives. The protective factors of patients are their coping skills, compliance with treatment services, and social support. With these protective factors and a stable social environment, patients will have better control of their symptoms and functioning. In turn, their stability and functioning will ease the stress for their relatives. The reduced amount of stress, plus the protective factors of the relatives (coping skills and support from social services), improve the family situation, which is a major social environment of patients. This framework highlights the reciprocal influence between relatives and their sick members, and is useful to conceptualize the 'reciprocal family-consumer relationships' described by Butterill and Paterson (1996). It is worthwhile to explore this relationship as most family studies of mental illness collect data exclusively from relatives and ignore information of the mentally ill member. Moreover, the relationship can be a resource that enables them to cope with the illness more effectively and thus helps the family recovery. Therefore, it is important to include both views in my study of family coping.

More recently, there is a trend to reconceptualize the burden of mental illness and coping within the theoretical framework of family stress. Family stress theory has been developed to understand how families cope and adapt to major changes in their lives.

The major theories are Hill's (1949) ABC-X model, and McCubbin and Patterson's (1983) Double ABC-X model (cited in Wikler, 1986). A is the stressful event, B refers to the family resources at the time of event, C is the meaning attached to the event by the family and X is the amount of crisis in the family. B and C are the buffering variables that protect the family from becoming dysfunctional. Hill's model pertains to acute rather than chronic stressors. Therefore, McCubbin and Patterson added the dimension of post crisis variables to describe the additional concurrent stressors affecting family's recovery. However, both models cannot fully explain the dynamic interactions among family members.

The recent development is to view family stress as a process proposed by Burr and Klein (1994). They view that family members interact to transform inputs into output with relative ease when the family is not experiencing stress. Inputs include energy, time, money and information, and output can be meaning, affection, growth, security and satisfaction. Families develop rules to carry out these transformation processes. Stress occurs when the family does not have the requisite variety of rules to comfortably transform input into outputs that meet minimum individual and family goals. The family will try to manage the stress by making different levels of change, such as to change a family norm, to change rules about how rules are made, or to have changes in family paradigms. The focus of this theory is on the transforming process guided by family rules rather than the interactions between family members.

Marsh (1994) applied Hill's ABC-X model to families of people with mental illness. Johnson (1994) viewed that the Double ABC-X model may be useful in ordering stress components of mental illness. However, they both used these theories to examine families only (without inclusion of members with mental illness). Moreover, these theories are unable to give insight into how the person with mental illness interacts with other family members in the process of coping. A stress-vulnerability-protective framework (Glynn & Liberman, 1990) allows one to examine both individuals with the illness and their relatives, and is more heuristic and useful in this regard.

2.6 Family Recovery Process

Due to the chronicity of schizophrenia, it is essential to put coping into a time perspective to see how families cope at different stages of the illness. Again, most literature which discusses responses to mental illness is from the perspective of caregivers. Terkelsen (1987) described families' response through time in ten phases (cited in Hatfield & Lefley, 1987). They are (1)ignoring what is coming (2)first shock of recognition (3)stalemate (4)containing the implication of illness (5)transformation to official patienthood (6)search for causes (7)search for treatment (8)collapse of optimism (9)surrendering the dream and (10)picking up the pieces. These ten phases can be grouped under the three stages proposed by Spaniol and Zipple (1994). The distinctive contribution of their work is to include reactions of both the member with the illness and other family members throughout the stages of discovery and denial, recognition and acceptance, and coping. At first, family members try to explain away the changes they see. The family gradually recognizes that their family member has a major mental illness and tries to seek professional help. As families begin to accept the illness, they experience a sense of loss. This feeling of loss is also experienced by the family member with the illness. The cyclical nature of mental illness makes acceptance more difficult. When the persistence of the illness becomes obvious to the family, they grieve over old hopes and expectations and begin to establish new ones.

Families try to cope with the illness and their emotions with the aim of readjusting themselves to manage the impact of mental illness. This recovery process is not linear; family members will recycle themselves through the phases and each individual member will recover at his or her own pace. Spaniol and Zipple (1994) held a positive view about the recovery - it is painful, but the outcome can be the emergence of a new sense of self and more connectedness to others. I agree with this view that the recovery involves development of a new sense of self, especially for the family member with mental illness. However, this new self may involve a view of the sick family member as a "patient". This new view is a devaluation of the self, and segregates persons with mental illness from other people. Smith (1990) stated that the assumption of patient status excludes the person from participation as a subject in everyday realities. In her opinion, psychiatric professionals are accountable for this loss of social capacity in patients.

2.7 Chinese Family and Culture

Koch-Hattem (1987) viewed that a given family's success in coping with a chronic illness depended on its previous level of functioning, its resources, the meaning it attaches to the illness, the resulting changes in the patient and the other family members, and its flexibility in the face of change. The particular meanings that family ascribed to a chronic illness vary with the family's paradigm and its beliefs about health and illness. How a family views the world and the illness is closely related to the culture from which it comes. Schwartzman (1982) viewed culture as the beliefs and values that maintain the pattern of interaction in a social system. The cultural background of a family and its exposure to other cultures shape the family's perception of the illness and how it copes with it. Since Chinese are well recognized as having strong family values, they are chosen to be the target of this study. Therefore, it will further highlight the 'family-consumer relationships' which are lacking in existing family literature on mental health.

Chinese hold a multifaceted view of the etiology of mental illness, including moral, religious or cosmological, physiological, psychological, social and genetic factors (Lin & Lin, 1981). The moral view has interpreted "misconduct" as a cause of mental illness. The member whose behaviours deviate from socially prescribed norms is considered to be abnormal. The family feels ashamed of its inability to control the behaviour of its member, and will call in community leaders to help the family to teach proper behaviour to the individual.

Taoist and Buddhist beliefs play an important part in the Chinese view of the cause of mental illness. Mental illness is regarded as punishment, incurred by the patient or his/her family members, by gods and ancestors. The family feels ashamed of the punishment and attempts to remedy it by prayers and offerings at Buddhist temples, and calling on Taoist priests to perform shamanistic rites.

The physiological theory views that the illness is caused by an imbalance of nature's opposing "Yin" and "Yang" forces. Traditional herb doctors will be consulted for restoring the balance through herbs and special diets. The family may also feel ashamed in its failure to perform its duty in protecting the member from disaster. The psychological factors of the illness include failure in love affairs, finance and career, death and mourning etc. Sexual frustration is also sometimes considered to be the cause, and in this case arranged marriage is seen as the solution. The biological belief in genetic transmission makes the family feel its name is tarnished and it is harder for its youngsters to marry. Lin and Lin (1981) held the view that the family's fear of exposing its shame to people outside the family is the origin of the stigma attached to mental illness in Chinese. This feeling of shame and guilt can also affect the help-seeking behaviour of Chinese.

The study of Lin, Tardiff, Donetz, and Goresky (1978) in Vancouver reported that the help-seeking pathway of Chinese immigrants included persistent family involvement, extensive utilization of traditional health care systems and extreme delay in contacting the formal mental health system. They suggested that the high tolerance of Chinese families to keeping the patient at home is a result of the sense of family obligation and perceived stigma attached to mental illness.

Bentelspacher, Chitran, and Rahman (1994) found that Chinese relatives favoured the coping strategy of indifference-tolerance/resignation (unusual behaviours were not perceived as a problem, or behaviours were accepted as unchangeable aspects of the illness) over a more constructive strategy. In addition, only Chinese among the three cultural groups (Chinese, Indians and Malay) in their study used the avoidance strategy. This study confirmed Cheung's view (1986) that Chinese families emphasize self-directed coping strategies and reliance on immediate family when faced with mental health problems (Bentelspacher et al., 1994).

There are not many studies about Chinese coping styles. Hwang (1977) has studied the coping strategies of Chinese with troubles in life in Taiwan (cited in Shek & Cheung, 1990). Hwang found that the coping strategies of Chinese could be categorized into five types: mobilization of personal resources, seeking help from social resources, appeal to supernatural power, or adoption of the philosophy of doing nothing and avoidance. Shek and Cheung (1990) considered that these coping strategies can be re-categorized into self and other focus.

As family is very important for the Chinese, it is extremely crucial to study Chinese coping from a family perspective. Lin and Lin (1981) made the following comment about the Chinese family:

> It is the bastion of their personal and economic security; it provides the frame of reference for personal and social organization; it controls all the behavioural and human relationships of its members through a clearly hierarchical structure and sanctioned code of conduct; it transmits moral, religious and social values from generation to generation through role modeling, coercion and discipline. It also offers a haven for safety, rest and recreation; it maintains the altar for ancestor and religious worship. The influence of the family on the lives of its mentally ill members is no less than it is for any one else. The handling of the mentally ill in Chinese society cannot, therefore, be considered without taking family context into account (p. 387).

Hsu (1985) also viewed the Chinese family as extremely cohesive. Family members depend on one another for support. The Chinese see the individual members' behaviour as inseparable from that of the family. A member's behaviour represents the collective qualities of the family, and includes the faults or virtues of the ancestors. If one member shows deviant behaviour, the whole family loses face. However, family sharing does not apply to emotion. Open expression or discussion of emotions is generally not encouraged, except in certain ritualistic situations such as funerals (Hsu, 1985). Actually, verbal expression of emotions in the Chinese language is predominantly centered on complaints about somatic symptoms.

The above review indicated that Chinese have a multifaceted view of the etiology of mental illness and that a feeling of shame is found in the family no matter which etiological model it held, as a consequence of strong family ties. The fear of exposing its shame creates the stigma attached to mental illness. Chinese tend to adopt a self-reliance coping strategy, and family plays an important role in seeking psychiatric treatment and the rehabilitation of the sick member. In the social context of Toronto, it is unclear to what degree Chinese values and beliefs are still being held among Chinese immigrants and how much influence these values and beliefs have on their coping with mental illness. It is hoped that the present study will give further insight into this concern.

2.8 Summary

The relative with a mentally ill family member is viewed most recently as a coper to the continuous stresses induced by the chronic illness. The perception of a person with mental illness is also changed from that of a passive care recipient to that of an active agent in coping with her/his illness. The needs of relatives and their members with the illness may sometimes be in conflict particularly over the issue of control. There is a shift of concept from the polarized view of relatives or ill members to an holistic approach, incorporating both perspectives. Furthermore, the literature currently available emphasizes particularly the impact of the mental illness on the relatives and their coping, and almost none of it talks of the experience of the sick member and the interaction of both in coping with mental illness. Therefore, a study to review this shift in concept and to explore the familial relationships is deemed necessary. The present study will try to explore how families as a unit (both the relative and the sick member) cope with one of the serious mental illnesses, schizophrenia, in the sociocultural context of the Chinese living in Toronto. Chinese families are chosen as the target because Chinese hold strong family values and will attend closely to familial relationships.

CHAPTER THREE

Conceptual Framework

Coping is defined as the efforts to manage the stressful situation resulting from the mismatch between environmental demands and resources of an individual or a system. It involves alteration of demands, individual or family resources, individual or family needs, goals and preferences (Hauser et al., 1993). Beside the coping strategies, social services and support are essential protective factors in the process of coping (Holahan & Moos, 1986; Glynn & Liberman, 1990). There are constraints in coping such as social stigma and the vulnerabilities of new immigrants. Schizophrenia is a persistent illness that extends over long periods of time and demands for an on-going coping. In exploring families' coping with this illness, this study uses the stress-vulnerability-protective model (Glynn & Liberman, 1990) to examine the issue from a process perspective, including dual perspectives of family interaction, and social support and constraints in coping.

3.1 Coping Strategies

There are different ways to explore coping strategies. Larazus & Folkman (1984) referred to coping as cognitive and behavioral efforts (cited in Holahan & Moors, 1986); Billings and Moors (1984) delineated coping responses into appraisal-focused, problem-focused, and emotional-focused (cited in Shek & Cheung, 1990), and Spaniol and Jung (1987) added the fourth dimension of physical focus (cited in Hatfield & Lefley, 1987). Pratt et al. (1985) examined coping strategies from external and internal dimensions; similarly, Shek and Cheung (1990) conceptualized coping responses as reliance on self and seeking help from others. Culturally based views on mind and body, and locus of problems and coping are significant. Some cultures may promote coping strategies for personal understanding of distressing emotions while others may have a broader concern in eradicating emotions (Fernando, 1991). Chinese families favoured self-directed coping strategies and reliance on immediate family when faced with mental health problems (Bentelspacher et al., 1994). This study thus looks into the coping response of Chinese families from the domains of self, family-reliance and external help.

Self-reliance coping consists of having self-confidence; adopting a philosophy of doing nothing; forbearance and perseverance; and solving the problem (Shek & Cheung, 1990). Family reliance coping refers to mobilizing help and support from other family members. This support may include a negotiation of change in family expectations and roles. The coping strategy of seeking external assistance means soliciting support from friends, neighbours, religious affiliations, organized support groups for relatives or consumers, health care and social services.

3.2 Coping As a Process

Families have various tasks to manage schizophrenia as it develops and goes through its course. Marsh (1992) described the time phases of mental illness as: i) the symptomatic period, ii) difficult period of adjustment following diagnosis, and iii) chronic phase. There are numerous dimensions to examine the coping process: focus on family's emotions and responses towards the illness (Hatfield & Lefley, 1987; Spaniol & Zipple, 1994), emphasis on role conflict and the ambiguity of immediate relatives as their members link with different supports (Hanson, 1993), and types of professional support required by relatives at different times (Kates & Hastie, 1987). The Chinese coping pattern is characterized by five distinctive phases: i) exclusively intra-familial coping, ii) seeking help from entrusted outsiders, iii) inviting outside helping agencies, iv) accepting specialist's help, and v) rejection and scapegoating (Lin, 1985). The rejection is a consequence of the loss of hope for recovery of the sick member and the unbearable burden of caring for relatives. One of the most burdensome behaviours for caregivers to cope with was found to be a product of the symptoms (Johnson, 1990). Therefore, this study attempts to investigate the coping process with reference to the control of symptoms with assistance from treatment.

3.3 Family Interaction

Literature reviews that persons with schizophrenia and their relatives affect each other. With the increasing role of caregiver by relatives as a result of the community care policy, this study seeks to know how families perceive this prolonged dependent relationship, what are the impacts on both the adult member with schizophrenia and his/her parents, and how they respond.

The onset of schizophrenia is largely in late adolescence and young adulthood, and thus disrupts the normal development towards self-sufficiency (Caton, 1984). Inadequate social functioning plagues the afflicted individual and poses stress for their relatives. Persons with schizophrenia are still rooted in a conflict between independence and dependency, as they have not fulfilled this developmental task (Hatfield & Lefley, 1993). They may evoke self-hatred or may displace their anger onto their parents. The parents' tendency towards protective response perpetuates the dependency of their members and reinforces the conflict of independence and dependency. Steve Kersker felt that this protective parental attitude actually blocked rehabilitation and recovery of consumers (cited in Hatfield & Lefley, 1993). Three types of parent-child relationships were revealed between adult mildly retarded persons and their parents: supportive, dependent and conflict-ridden; the type of family context was suggestive of the mentally retarded adult's adaptation to independent lifestyles (Winik, Zetlin & Kaufman, 1985). This study explores the interaction between people with schizophrenia and their parents in similar fashion.

3.4 Support and Constraints in Coping

Adaptive coping of relatives has been found to be associated with increased social support (Solomon & Draine, 1995). Professional assistance was emphasized to meet relatives' needs in knowledge, skills, and emotional support (Anthony & Nemec, 1984). Persons with schizophrenia require pharmacological treatment to reduce their symptoms and rehabilitation services to develop their skills in order to function in their environment (Davis & Gierl, 1984). The disorder is viewed as being modified by the coping and competence of the individual, and by a supportive environment (Liberman et al., 1987). Support to afflicted individuals not only enhances their functioning, but also reduces the objective burden of their relatives. Services to relatives will strengthen their coping abilities and capacities to provide a more supportive familial environment. Social support plays an important role in shaping family relationships particularly between the afflicted members and main caregivers.

In building one's social support, there are issues of availability and accessibility. Services may be inadequate to cover the demands or insensitive to the person's needs. It is harder for minority groups to get access to services due to institutional barriers such as lack of staff who speak their language. The accessibility is further limited for new comers to Canada. Their barriers to using mainstream services include lack of information, unfamiliarity with the physical environment, cultural differences and language problems (Stevens, 1993). In dealing with mental illness, the strong social stigma attached to it by Chinese may defer their seeking for professional help (Lin et al., 1978). Their feelings of shame and inferiority may also affect their social network.

3.5 Summary

This study examines Chinese family's coping from the dual perspectives of aged parents and adult children with schizophrenia. The disorder is long-term and requires ongoing management. Coping theories and studies focus on the protective factors of coping: coping skills, familial and social support. In this study, coping strategies, family interaction in coping, and support and constraints of coping will be explored in the context of coping processes over time.

CHAPTER FOUR

Methodology

4.1 Research Design

The purpose of the present study is to explore how Chinese families cope with schizophrenia. Chinese families are defined as ethnically Chinese individuals with the illness, plus siblings and their spouses (if any) and parents, who use the Chinese language as their major media in their daily communications. Their coping may be affected by their perception of schizophrenia, the way family members interact, and their willingness to get resources outside of the family. These views and behaviours are in turn shaped by their cultural values and beliefs, family environment and the social context of Toronto. To have an understanding of how families cope with reference to their cultural and social context, it is best to look into it from the perspective of the families themselves. Therefore, this study uses a qualitative approach. Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter (Denzin & Lincoln, 1994). It is used in capturing an individual's perspective and in gaining an in-depth understanding of phenomenon in question. Taylor & Bogdan (1984) view that qualitative research studies people in the context of their past and the situations in which they find themselves. The focus of this study is on the process of coping in families. This coping is so complex that it involves beliefs, family interactions and mobilization of resources. It demands an in-depth exploration through qualitative research.

The target of this study is families, which are a distinctive social group. The unique nature of families is composed of : privacy; a collective consciousness that is not readily available to non-family members; relationships rooted in blood ties, adoption contracts or marriage, and intended to be permanent; shared traditions; intense involvement, and a collage of individual interests, experiences and qualities (Gilgun, Daly & Handel, 1992). The qualitative approach facilitates a holistic study of families. This means looking at behaviours and interactions within a family context rather than at variables that isolate particular fragments of family experience.

4.2 Data Collection Strategies

Qualitative research is flexible enough to allow for the use of multiple methods of inquiry, and in-depth interviews are frequently used. An interview is a useful way to get large amounts of data quickly. More than one person can be used as an informant in the interview, and the interview process allows for the gathering of a wide variety of information and for immediate follow-up questions (Marshall & Rossman, 1989). Interviews have great value in understanding people's experiences, feelings, and intricate interactions with their social environment. As I am interested in knowing the individual family member's perspective and how they work together in managing schizophrenia, in-depth family interviews were used for data collection. The family interview included two key informants of each family, the person with schizophrenia and one other family member, so as to get a comprehensive view from the family. Participants are interviewed independently with the aim of creating a conducive environment for them to talk freely about their feelings and experiences without worrying about the presence of other family members.

My working experience with families has shown that emotionally charged families need a guideline to focus their discussion, while less expressive families needed a guide to encourage them in talking more. Therefore, the interviews are semi-structured in this study. This meant that general topic areas were probed to some degree with all participants, depending on the extent to which the topics seemed meaningful to them and relevant to their experiences (Gilgun, Daly & Handel, 1992). An interview guide was developed to make sure key topics were explored with informants (Appendix B). How questions were phrased and when were asked depended on the particular interview situation. The interview guide was expanded following the first few interviews. Demographic information was collected at the end of the interview (Appendix C).

4.3 Selecting Informants

Interview participants were recruited from the agency with which I am professionally involved (since it is the only community mental health agency in Toronto specifically serving the Chinese, Vietnamese, Cambodians and Koreans). Using this agency as a site to enlist participants ruled out families who have never used community resources. As it is hard to incorporate families at different family life cycles in one study, and due to the fact that the clients of this agency are mostly single and fall into the age group of 25-44, families of aged parents with an adult schizophrenic child whose age is within 25-44 were selected as participants. Besides the person with schizophrenia, the other key informant can be the father or mother (whomever named by the person with schizophrenia). Since I am only fluent in Cantonese, only Cantonese-speaking participants were interviewed. Families from the northern part of mainland China or Taiwan were excluded since the primary language used in these areas is Mandarin.

Any families on my caseload were excluded from the study so as to avoid any confusion of my roles as social worker and as researcher. The level of functioning of persons with schizophrenia was not a selection criterion in this study, with the exception of mental stability which was a requirement to avoid any possible harm to the informants and to enhance the credibility of the study.

Direct methods of issuing or posting invitation letters to potential participants do not generally elicit a positive response within the Chinese community. Consequently, a personal approach was utilized to recruit participants. My co-workers identified families from their existing clientele and asked permission from potential participants to have me contact them. In order to avoid the problem of possible coercion by my co-workers over the potential participants, my co-workers had stressed that the study was a project of a student at York University and their participation or non-participation would not affect their services at the agency. With the support of the Executive Director of the agency, I explained the study to my co-workers during a staff meeting. This meeting was essential as it clarified some of the concerns that my co-workers had, such as the eligibility, my role and interview procedure.

4.4 Research Procedure

After obtaining the names of potential participants from my co-workers, the families were contacted by telephone (both the persons with the illness and their parents – with one exception: where it was inconvenient for a parent to receive a call) to inform them of the objectives of the study, and to ask for their consent to be interviewed. A telephone contact was preferred because it was less formal and facilitated the voicing of individual concerns and initial engagement for the interviewer-interviewee relationship. Interviews were scheduled once the family agreed to participate in the study. The place and time of the interviews were chosen by participants at their convenience and for their comfort. Most persons with the illness preferred and were interviewed in my office while their parents preferred and were primarily interviewed at their home. In two families, both parents attended the interviews together and in another an elder brother participated in the interview with his mother as well. Each interview lasted for approximately one to two hours. In this study, I interviewed eight families; a total of 16 interviews of individuals with the illness and their parents were conducted. At this point, I found the saturation point was reached and further interviews would not add new information. All interviews were conducted within nine months from December, 1995 to September, 1996. Three family interviews were carried out first to check the interview guide and other planned interviewing procedures, and to have some initial data analysis before moving on with other interviews.

I presented myself in the interview as a student of York University who was interested in learning from them about their experiences. This was with the aim of minimizing status differences in my other role as an agency social worker, and the participants' role as service recipient. To observe the ethical principles of voluntary participation and informed consent, the study was explained again and an 'informed consent form' (Appendix D) which was translated into Chinese was given to the participant to sign before the interview. One mother refused to sign as she was uncomfortable with the formal procedure. However, she verbally permitted me to interview her. Participants were also informed that they could withdraw from participating in the study at any time and they could decline to answer any questions about which they felt uneasy. I also obtained their consent to record the interviewing process with audio tape. One parent felt uneasy about having the interview recorded. In this case, I took notes during the interview.

During the interview process, most interviewees regarded me as someone who had special knowledge in the field as they all knew I work as a social worker in the mental health field. With knowing who I am, they were very open to talk about their experiences. It is an advantage for me to be an insider of the agency since persons with schizophrenia would not agree to be interviewed by an outsider whom they do not know or trust. While trying to stick to the researcher role, I was asked for help by a few participants at some points during the interview and a few parents sought consultation about their concerns. Efforts were made to answer their questions and offer informational help at the end of the interview.

Though it was expected that people had differing abilities to provide detailed accounts of their experiences and feelings, I had problems in two interviews with persons with the illness. These two interviewees seemed unable to elaborate on their answers. This might be due to their poverty of thought or speech (a frequent symptom of schizophrenia). I had difficulty in formulating questions based on what they said and thus decided to ask more closed-ended questions. My experience in dealing with chronic clients in interviews at work is less a problem (in a social work context, wherein it is acceptable to have the worker's interpretation of the problem and then check it out through the working process). In a qualitative research project (wherein it is important to get the interviewee's individual perspective), an interviewee suffering from schizophrenia with symptomatic difficulty in verbal expression poses a significant problem for data collection purposes.

I transcribed the interviews in Chinese. To protect the interests of all the participants, all the information collected was held strictly confidential. Identifying data were changed in the transcription, and the identification list created was only available to me. Both the transcription and tapes were kept in a safe place. The tapes will be erased when the thesis project is completed.

The persons with schizophrenia are primarily in their thirties and forties. Five are male and three female. Six of them are single, one is separated and one is divorced. Only one of them has a university education while none of the others completed high school. Their stay in Canada varies from two to sixteen years, and their places of origin are Hong Kong, mainland China and Vietnam. Five of them were sponsored to Canada by their siblings, and one by her fiancée. One came with his wife as her dependent, and one landed with his brother as a refugee. Three of them have been sick for less than five years and one for less than ten years, and the remaining half for ten years or more. Two of them reported symptoms of schizophrenia before immigrating to Canada; the other six were diagnosed within the first few years of their arrival. Five have had one admission to hospital, and two have had more than one hospitalization, while the remaining one has never been an inpatient. Most rely on government financial assistance as their main source of income, and two manage to have additional income from part-time employment. Most of them are living with relatives (usually their parents).

In order to include the relative's perspective, one of the parents of the person with schizophrenia was interviewed separately. The father is deceased in two families, one of the mothers participated in the interview together with her son. There were two situations where both parents presented at the interview but, in each case, only one of them acted as a spokesperson. The spokespersons are mainly the caregivers. These are five mothers and three fathers, and most are the primary decision makers in the family. For the mother who came with her son, her family is very cohesive and responsibilities and decisions are shared. All families have at least three children, and three families have six to eight children. Other than the persons with the illness, no other children in any of the families have any disability. These children offer varying degrees of help, from no support to high levels of involvement, to their parents in caregiving. Three parents reported that their spouse cannot give them much support and two of them referred to the additional stress of handling a difficult relationship with their spouse. Besides the stress of the illness, most families have the extra pressure of relationship and communication problems within the family, as well as financial constraints. Many parents do not have jobs due to their age, physical limitations and disadvantages of being new immigrants.

In the Ng family, the parents are in their 60s and 70s and are retired. They are mainly financially supported by their children. They live with the two children who are still single, and one of these is the member with the illness (Kwong). Their children offer different support to them. For instance, the eldest daughter sought social services for both the member with schizophrenia and for the parents in coping with the illness, and the other daughter and her husband sent the member with the illness to hospital when he was in an acute state.

In the Ho family, the father has died and the mother is in her 60s. She is retired and lives on government allowances/assistance for seniors. She lives with her eldest son and his family as well as her other son who is single. The member with schizophrenia (Hon) and the youngest son live together with the objective of training the member with the illness to be more independent, while at the same time, providing some necessary support. It is a cohesive family, and all siblings have been involved in coping with the illness in the family especially at the discovery stage of the illness.

In the Tam family, the parents are in their 60s, and the mother has a casual job while the father cannot find a job. They live with three sons who are all single including the member with schizophrenia (Tak) in a two bedroom apartment. They manage the illness mainly by themselves.

In the Leung family, the parents are in their 70s and are retired. Their main source of income is from rent. They live with their member with schizophrenia (Bill), and there are tenants in their house. The mother did not find much support from her husband in dealing with the illness. Their daughter and her family supported the member with the illness for some time when they lived together.

In the Mak family, the parents are in their 50s. The father cannot find a job and the mother works in a factory. They live with their son and the daughter with schizophrenia (May) and her two children in metro housing. The father is the main care giver and feels that his wife is unable to provide much support to him. His son helps when he has to communicate in English with service providers, or when he is not available to support the daughter.

In the So family, the parents are in their 60s and are retired. They live on government allowances for seniors, and they find themselves financially comfortable. They reside with their daughter with the illness (Nora) in their own house. Their son offered support to the member with the illness in Hong Kong when the parents were in Canada. The mother is the main caregiver and she finds her husband lacks understanding of their daughter's illness.

In the Lam family, the parents are in their 50s. The mother is a homemaker and the father cannot find a job. They are financially supported by their children and find themselves to have a tight budget. They live with their son with schizophrenia (Lap) and the other son who is single. They manage to take care of their member with the illness and do not need help from other children.

In the Fung family, the mother is in her 70s and the father has died. The mother lives on government allowance/assistance for seniors. She has three children, and resides at her son's residence together with his family and her daughter who has lost a job and has moved back. The daughter with schizophrenia (Fong) lives alone in metro housing. The mother and the sister visit her weekly, and the sister has lived with her in the past and helped her in getting social services. The mother showed disappointment towards the son and his wife, and there are relationship problems in the family. The son and his family have given very limited support to the daughter with the illness.

5. Data Analysis

Analysis includes the procedures of organizing the data, generating categories, themes, and patterns, testing the emergent hypotheses against the data, and writing the report. Initially, I tried to examine the data in different ways: looking for common issues from data collected from persons with the illness and parents separately, and finding similar topics of families (i.e. putting both key informants' data together in an unit). The data were read and re-read to record for recurring activities, ideas and feelings. Literature was referred to for the framework which provided a basis for analyzing the data and suggested variables to code the data. Salient themes, recurring ideas and patterns were identified and were listed to develop coding categories.

The coding process involves bringing together and analyzing all the data bearing on themes, concepts and interpretations (Taylor & Bogdan, 1984). I endeavored to interpret the thoughts, feelings and actions from the family's perspective to avoid imposing my view onto them. As I come from the same ethnic community as the families, it was easier for me to understand and to share their perspectives. The Chinese transcript was coded for data organization and data analysis. Several copies of the transcripts were made for using "The Cut-Up-and Put-in-Folders Approach" (Bogdan & Biklen, 1992). Two sided folders were used, one side for data from persons with schizophrenia and the other side for their parents. Each folder was named after the coding categories, and each coded bibbit was cut and put into respective folder and its side accordingly. Bibbits in each folder were sorted out to connect with one another for themes, patterns and relationships. A coherent understanding of the data was formulated by building a logical chain of evidence. This conceptual understanding was also compared with relevant constructs in the literature.

At the time of writing the analysis, the quoted bibbits were translated into English. This translation process presented two problems. The first of these problems was the issue of translating Chinese idioms which express emotions into their English equivalents. Chinese culture has valued control of emotions, and fewer emotional words developed; instead, Chinese often use physical metaphors to describe their emotions (Cheung & Lau, 1982). The second, and far more complex, problem concerned the differences in the way in which Chinese and English speaking people express themselves. Chinese typically choose subtle, perhaps vague language in which the true meaning is frequently hidden in the space "between the lines". As a Chinese interviewing Chinese participants in the Chinese language, it was relatively easy for me to grasp the subtleties of the language and the mode of expression. Translating these ideas into English, however, required that I make the language far more concrete in order for it to be meaningful to English speaking readers. Such translation is, of necessity, an extremely subjective process. At the same time, I did my best to maintain the essence and the manner of expression of the participants.

Findings of this study and their analysis were presented and organized by theme in the following chapters.

6. Soundness of the Study

The cannons to measure the trustworthiness of qualitative research are credibility, transferability and confirmability (Marshall & Rossman, 1989). Credibility is usually obtained from the discovery of human experiences as they are perceived by informants. A study is credible when it presents accurate description of human experiences. In analyzing the data, I was aware of a tendency to put families in a positive role. This awareness alerted me to be very critical with my interpretation of the data. In order to ensure the credibility of this research, the analysis was checked by a few key informants and colleagues. One problem in this study is that a few persons have been sick for a very long time and it is hard for them and their parents to recall their experience at the very beginning of the illness.

Transferability is to show that one set of findings on one target group is applicable to another similar population. Outlined here is the context within which this study was carried out: aged parents as main care givers to adult children with persistent and severe mental illness, first generation immigrant families, the members with illness are having psychiatric treatment and have used or are using community mental health resources, and both parents and their members with illness agree to be interviewed separately. Moreover, this study may be useful for social worker practitioners to know how Chinese families cope and what kind of help they require. It may also be helpful to policy planners or program developers to have an understanding of what services are helpful and what barriers exit for Chinese families in coping with this persistent and serious mental illness. This understanding of the coping process can be generalized in theoretical sense.

Confirmability refers to the concept of objectivity. It concerns whether the findings are reflective of informants and inquiry itself rather than the product of the researcher's biases. It is achieved when credibility and transferability are established (Krefting ,1991). The cross-check by a few informants and my colleagues helps to reduce my personal bias in the interpretation of collected data. Families with whom I were working were excluded from the study as I were familiar with them and thus might loose my sensitivity due to preconception of them.

Throughout this research, efforts were made to achieve the highest level of trustworthiness.

CHAPTER FIVE

High Degree Of Relative Support

A high degree of relative support is the common theme identified throughout the process of coping with schizophrenia. Three stages of coping are found: discovering the illness, linking with treatment, and maintaining the stability of the illness. Both people with schizophrenia and their relatives use various strategies to cope with the illness. These strategies may be grouped into three major categories: employing personal resources, using resources within family, and requesting help from other resources.

5.1 Discovering the Illness

The great majority of persons with schizophrenia and their relatives did not have any prior knowledge of schizophrenia. Relatives played a key role in discovering the illness, and in seeking external help when families felt unable to manage the problem.

5.1.1 First Experience of Schizophrenia

When the illness first started, there were changes experienced by the person or observed by their relatives. These changes were gradual for some participants and sudden and acute for others. The changes included the experiencing of symptoms, a decrease in general functioning and the exhibition of socially inappropriate or unacceptable behaviours. The symptoms are hearing voices, seeing internal "movies", feeling scared and anxious, having delusional and paranoid ideas, and the inability to sleep. Persons with the illness described their early experiences of symptoms and how they deal with them:

> I felt that some one was following me, and wanted to catch and hurt me. I was very anxious for about a month. I later found that I could not put up with these pressure and bought a plane ticket to go to my sister's place. After I arrived I still felt anxious and scared about being followed by someone. My sister and her husband took me to see a doctor. (Bill)

> I felt very bad in university. I was sick at the time, I heard voices and I had no friends again. I sat in the last row of the class in the corner seat. I heard someone talking to me and calling me Chinese, China. The voices were related with racial issues. My brain found the white people didn't treat the Chinese well. I regarded the white people as enemies and rejected them. I heard the white people commenting on the Chinese negatively. I told myself that Chinese were excellent as they defeated the Americans. The Americans lost the war in Vietnam and Chinese won in Korea. ....This made me more socially isolated. If people did not belong to my group, they were enemies. Images of racial issues came to me in the voices. I did not take English, and took mathematics again. I had problems in that these courses required experiments and group work....I could not make it through after dragging for 2 years and half semester. In the last semester, I was really sick. I moved to live in a youth hostel. My thoughts were preoccupied with women and sex. I was really ill. I heard people calling me in my room. One time, which I had planned for a while, I exposed myself....Bad! People knew that I had exposed myself, and chased after me. I heard people commenting about me "Exposed!" in the class, and the entire world knew that I did it. I was really scared, and my heart beat fast. All people said that I exposed myself. I had no place to hide, and I phoned my sister to tell her what I experienced. (Kwong)

> I found myself afraid of people. At first, I did not think it was a problem. I thought that it might be an adjustment issue or psychological response and did not tell my sister about it. Gradually, I felt more scared of people and events all day long. I felt I had to tell my sister. (Hon)

The persons with schizophrenia were greatly affected by their symptoms; they felt scared and pressured. The illness was so overwhelming that they felt powerless to handle it. Some were initially aware of their stress, and tried to endure their sufferings, explained away their problems, and moved from one place to another. When they gradually felt unable to handle their symptoms, they turned to their relatives for help. Among the remaining participants, most were not aware of their situation. They relied on their relatives to discover their problem. Relatives noticed the change in members' functioning more than the presence of symptoms. They found that their members with schizophrenia had experienced deterioration in numerous areas of functioning such as having problems in studying, keeping a job, taking care of themselves or others, and socializing.

> She was sick and slept all day. She did not want to cook or to do any other things. She did not take care of her two daughters, leaving them unattended to play with clothes and throw food around. (Mr. Mak)

> We did not know what Nora was thinking. She might have been sick but we did not

> know about it. She could not keep her jobs one after the other. Her father suggested to introduce her to work at his factory as she could not continue to have so many jobs. (Mrs. So)

Relatives tolerated the gradual changes and tried to manage the situation within the family as they did not recognize that the changes were symptoms of mental illness. Once the symptoms became even more disturbing or more drastic behaviours occurred, relatives then sought external help from friends, immigrant services, general practitioners and psychiatrists.

> At the beginning of his illness, it was not obvious. He thought that people wanted to fight with him. The kids in the neighbourhood actually did not provoke him to have a fight. He later became more serious, said that he heard someone all the time ask him to do something. He quarreled and got into conflict with people. We saw this situation, and brought him to see a doctor. (Mr. Tam)

> When my daughter stopped working, she started to have sleeping problems every night. She could not go to sleep, and thus got up to have drinks, to look at herself in the mirror and to go to the bathroom. These behaviours were pathological.... As she could not sleep every night, we took her to see a psychiatrist. (Mrs. So)

> He treated the family as his enemy...We were afraid that he might lose control of himself. If he hurt someone, that would be too late. (Hon's brother)

> My wife one day saw my daughter hit a stool with an axe and I had seen that behaviour before. My wife asked her not to hit the stool but my daughter was angry with her. She said that it was none of her business, and threw the stool and the axe towards her mother. She could not manage her personal hygiene as well. She was having the period and messed up the bathroom. I felt that she was sick. I tried to get a friend to drive her to see a doctor on the following day. (Mr. Mak)

In acute onset, relatives sought external help promptly.

> He did not eat and did not sleep for a few days. He had a delusion that he could survive without food and sleep. He stood facing the wall for days and nights. When he could not take the long standing, he knelt down. I asked him to go to bed; he said that he could not go to sleep and he would die once he lied down to sleep....We were worried and took him to see a doctor. (Mr. Lam)

It seems that both the persons with the illness and their relatives used the coping strategies of using personal and familial resources at the beginning because they were unaware of the meaning of the gradual changes. In the cases of acute onset, relatives were alarmed by the unusual behaviours of their members and responded relatively quickly to get external help.

5.1.2 Difficulties in Getting Treatment

A few relatives experienced tremendous amounts of stress due to not knowing where to get help.

> We did not know what to do and where to get help, and thus delayed the treatment. We felt very bad that we did not know what to do. (Hon's brother)

A few relatives called around and got information from social service agencies and some figured out to take their members to see a general practitioner while the others took their member to hospital. In one situation, the general practitioner did not assess that their member had any problems and the relative got stuck with the situation. The relative called the police when her daughter's problems further deteriorated. The police defused the situation and left as her daughter was not hurting people. This relative felt helpless but the situation demanded that she kept on seeking help.

Relatives had problems getting to see a psychiatrist, and even greater problems in getting a psychiatrist who speaks the Chinese language in the small town where a few discovered their illness. Toronto has more resources but even here there is a limited number of Chinese psychiatrists, and there is a long waiting list. A relative felt powerless with the appointment for his daughter in a month's time.

> This illness is different from other illnesses, people with the illness can die in a month. However, the nurse told me that our appointment date was already quite early. Nothing I could do, even if I had money. Just like a Chinese idiom, no way to talk about bitterness. I had to swallow my feelings. (Mr. Mak)

In an acute mental condition, one participant required hospitalization, but there was no hospital in his neighbourhood that had a Chinese speaking psychiatrist. It was arranged for him to be admitted to a hospital outside his area because of the language problem. His siblings felt lucky that their father could learn the way to go to the hospital. If the father did not know the way and other siblings could not have time off from work, they had to choose from two unsatisfactory situations: having psychiatric treatment for their member in his language but no constant family support due to the limitation of distance, or not having treatment in his language but family support.

Individual relatives had extra stress when their member with illness refused treatment.

> We felt ambiguous that we could not kick our family member out, but we could not help him by letting him stay home. (Hon's brother)

Relatives used various means to get their members to treatment such as persuasion, making use of close relationships with the sick member and lying.

At this discovery stage of the illness, persons with schizophrenia were unaware of their situation or felt powerless to handle their illness, and relied on their relatives to take care of them. Their relatives reported high stress levels. The stress not only came from the increasing symptomatic behaviour of their members, but also from their lack of knowledge about the illness and social services, and the unavailability of psychiatric treatment provided in their language. Relatives had additional stress when their member with the illness refused to accept treatment. They had a feeling of powerlessness particularly in obtaining access to psychiatric treatment. They were anxious about the situation, felt fearful that the condition of their member might become worse, and guilty that they might have delayed the treatment due to their ignorance.

Relatives tried to manage their problems through family discussions, close supervision of their members with illness, talking to friends, calling around for information, taking their members to general practitioners, sending their members to hospital, and using various means to get their members to see a psychiatrist. They made tremendous efforts to cope with the illness by using resources within and outside of the family.

5.2 Linking with Treatment

When persons with schizophrenia were connected to treatment, each individual had a different response. Some found it very helpful and reported that it reduced a lot of their symptoms without noticeable side effects. Some complained about the side effects of medication even though it was effective, while others found themselves to have residual/persistent symptoms even with medication. At this stage, they tried to manage their symptoms, side effects of medication and impairment of their functioning. They also struggled with acceptance of their illness, were concerned about the prognosis and felt confused about how to re-establish their life. Their relatives helped them to go through the difficulties with understanding, support, practical assistance and seeking community resources for them. Relatives also needed to accept the illness and to manage their own emotions. Their emotions related to their acceptance of the illness, the condition of their members and their impairment, and how their members handle their illness. They reported feeling more stress when their member with illness refused to take medication and relapsed, or when the illness was more episodic.

5.2.1 Managing Residual/Persistent Symptoms

Persons with illness used different ways to manage their symptoms. Some trusted their psychiatrists and gave feedback to them, complied with medication, endured the symptoms, and used the hospital as a shelter.

> The illness was strange. Hospital was a shelter for me. Once I got into the hospital, my stress was gone. Staying in a hospital for one to two weeks, I calmed down. However, I felt bad again after discharged. Therefore, I have been in and out of the hospital all the time. (Bill)

With all these efforts, some of them still found their situations unsatisfactory. A few felt powerless with their persistent symptoms.

> I let the illness take charge. I have no ways. What can I do? The psychiatrist also has no ways. (Fong)

Their relatives offered the suggestion of ignoring the symptoms and controlling oneself, of not being affected by them.

> You now know that this is your delusion. When you have this, you tell yourself that it is unreal. You try to control yourself: knowing that it is from your thinking and not believing in it. (Mrs. Leung)

At the same time, relatives were very attentive to their members. Mr. Mak arranged to live with his daughter so that he could monitor her condition. Mr. Lam took note of his son's condition and reported to the psychiatrist. A person with the illness recalled his relative's support as:

> Even with medication, I still had hallucinations, heard voices and experienced other symptoms of mental illness. I have no other way except to be patient. I slept all day on bed and I found it very hard to be on bed. Yet, my family was very good to me. My mother accompanied me continuously, and woke me up for medication and gave me

> water. I had good feelings about it. My elder brother came home from work late, and still asked about my condition. I knew about it, and I found the family was very important to me at that time. (Hon)

In addition to providing concern and support, relatives took their members for psychiatric follow-up, and talked to the psychiatrist about their observations and concerns. Most persons with the illness eventually found a Chinese psychiatrist and communication ceased to be a problem.

Relatives sent their members to hospital when they became psychotic.

> One night, my son yelled and screamed. He said that he saw a ghost, and I had to call the police to send him to the mental hospital. (Mr. Tam)

In dealing with the sleeping problems of their members, they reminded them to discuss it with their psychiatrist or assigned a bedroom solely for them to avoid disturbances to other family members. Mr. Tam dealt with his son's irritable behaviour with acceptance and advised him to join activities which he considered as helpful to his mood.

5.2.2 Managing Side Effects

Some persons with the illness complained about side effects of medication which might make them feel tired, sleepy, and dizzy, have blurred vision and a heavy head. They used determination to try to overcome these effects, diverted their attention by doing house chores, and consulted their psychiatrist about them. Their psychiatrists adjusted the medication or gave them suggestions. Hon described his side effects:

> I was very sleepy, and I listened to my psychiatrist to try to overcome them by myself. As the coffee did not help, I learned to have confidence in myself. I used an alarm clock to wake up myself or asked my mother to remind me to get up.

Relatives also gave support to their members to cope with the side effects. A few relatives posed a cautious attitude towards medication and inquired about side effects from psychiatrists or pharmacists as they believed that medication was not totally beneficial.

5.2.3 Managing Impaired Functioning

Most participants' mental condition improved with medication, yet they still had problems in daily functioning. They could not hold a job for long and found school work demanding. A few even could not travel around the city as they had problems remembering street names and feared crowded situations, and also could not concentrate due to the interference of symptoms. Their coping strategies were "nothing they can do", "let illness take charge", taking it easy, accepting their limitations, walking to the place, careful assessment before making new attempts, going out more to overcome the fear, and relying on relative's support.

Their relatives were supportive to take them around, to do things for them, to set appropriate expectations towards them and to comfort them.

> My daughter easily becomes emotional, and thus I go with her ways for most of the things and do things for her. When she had big problems that she could not handle, I ask her not to be afraid. I tell her, "I will solve any problem for you. I do not know English but I know the ways to solve problems and I also can consult the social worker"...I comfort her and her illness needs great comfort. (Mr. Mak)

There were at times different views of handling such problems within the family. A few parents had to help their spouses and other children to understand the limitations of the illness on the sick member, and to be a mediator to prevent conflict. Mrs. So reported,

> I ask him (my husband) to take it easy. 'You are already so old, and you still do not accept.' I am the middle person to solve the situation. When her father criticizes her, I ask her to go upstairs to sleep. It is lucky that the housing condition is good.

5.2.4 Accepting the Illness

Most participants accepted their illness as it occurred, and did not think that they had any control over it. Some perceived that it was their fate to have the illness or viewed it as a physical problem. A few attributed their illness to an accident or social isolation. Hon talked about his illness as:

> Fate means that I have no way to control my life. I am not comparing myself with other people, I am a person and why I am unlucky to have the illness? I can do nothing. If I have the illness, then I have the illness. Maybe I don't want to have the illness. Who would want to have the illness? If you have it, then you have it. Merely fate.

Even with these explanations, some persons with illness still had problems in accepting their illness. A few participants felt lost, hopeless and depressed when they realized the true nature of their illness. They did not know when his illness would be cured and felt unable to have any plan.

> I got lost. I did not know what I could do, I had no money and no job. The economy was not good, I stayed all day at home, watched TV, ate and slept. I did not go out. I had stayed home for the entire month without going out. I did. (Kwong)

One was very depressed and attempted suicide twice. A few felt great stress in having psychiatric treatment, due to the social stigma of mental illness. They simply denied their illness and explained it away with psychological reasons or evil spirits. These coping strategies of avoidance and denial eventually became stressors for their relatives.

One relative who was very sensitive to his daughter's feelings had a better understanding, and explained the illness to her in physical terms to make it easier for her to accept the illness. Many relatives did not understand why their members hide themselves at home, tried to kill themselves, denied their illness, and did not take the prescribed medications. They were worried; they persuaded their members to take medication, tried to stop them sleeping, got them out of the house, looked for help from other children and an ethnic community mental health agency. A few relatives got into conflict with their members over medication compliance or let them to have their own choice.

> He all the time said that he did not have a mental illness and it was merely a psychological problem. We did not know at the beginning and also thought that it was psychological. We assumed that he would become better after leaving the communist rule of Vietnam, and did not pay much attention to him. Nevertheless, he did not go out and did not talk to family members, and slept all day after he came to Canada. One day, the weather was good and I asked him to buy a newspaper with the purpose of getting him out to relax. He went out for a long time and did not come back home at night. We were scared and reported him to the police. After a day, we received a call from a hospital who informed us that they had a patient looking similar to our son and suggested that we go to have a look. We saw him in hospital and he had already poked his eye out. (Mr. Tam)

Not only the persons with the illness had problems accepting their illness, but also their relatives. For example, they tried to cope with this issue by comparing their member with serious cases, having optimism about possible recovery, focusing on the positive progress of their members, thinking that they were not alone and many others had similar problem, telling themselves that it was an illness and was not a crime, and channeling their emotions to problem solving. Mr. Mak described how he managed his emotions and consoled his wife:

> You can think your way through anything. Anything in the world, there is someone with similar situation. It is not only our daughter who has the illness, there are many other people who have the illness. There are examples for you to see in mainland China and here. Why should we be worried. Even my son he is afraid, it is his sister. He fears that people know about his sister's illness and no one will marry him. He has this cognitive burden. I say 'do not be afraid. This is the reality, there is no use to be afraid.' No matter how pessimistic and painful you are, it is no use. Because this is the reality.

Accepting the illness is difficult for both persons with the illness and their relatives. It is especially hard on the relatives. On the one hand, they have to help their members to accept the illness and to manage their non-compliance to treatment. On the other hand, they have to deal with their own acceptance and related emotions of worries and shame.

5.2.5 Re-establishing Lives

Most persons with the illness tried to re-establish their lives after the onset of their illness with help from a community mental health agency. They linked up with this support through their psychiatrists, hospital social workers, and their relatives who found out about this support by reading newspapers, talking to friends and calling around.

> I order a newspaper to read every day. I saw information about the ethnic community mental health service, and I cut it out for my son to read. I also called this agency to get someone to help him and took him there. (Mrs. Leung)

The mental health workers linked them up with other community resources to build up their daily routine, and they went to English-as-a-Second-Language classes, sheltered workshops, and vocational training programs.

Some relatives tried to have a better understanding of schizophrenia to enable them to cope with the impact of it. They read relevant information in the newspaper, or attended educational workshop and groups.

At this stage, persons with the illness tried to manage their illness and its impact with various approaches. Some were more active in doing what they could while others adopted a more passive response. However, they all relied on the support of their relatives to go through this stage. Their relatives provided great support to them to adjust to the new life after their connection with treatment. They also sought assistance to build up their knowledge and skills in dealing with the illness.

5.3 Maintaining Stability

After linking to treatment, the mental condition of the person with the illness is generally more or less stabilized and they have tried to reestablish their lives, which have been seriously disrupted by the onset of their illness and hospitalization. The following stage which is commonly found in participants' comments is what I have called the 'maintaining stability' stage. At this stage, persons with the illness continue to manage their illness to be stable and move on with their lives to express their potential to the fullest possible extent. In order to achieve these goals, they monitor their mental condition with treatment compliance, build a routine structure for their lives, and try to prevent relapse by reducing life stressors. Concerns about their future and handling of their emotions are reflected (especially by their relatives) in this maintaining stage. In the majority of families, relatives' support is not much less than the previous two stages.

5.3.1 Monitoring Mental Condition

One of the common strategies that the participants use to maintain the stability of their illness is monitoring their mental condition with treatment compliance. They attend psychiatric follow-up and take prescribed medication. They mark down the date of follow-up on the calendar to remind themselves. They also take note of their condition, and discuss their concerns with their psychiatrists about social skills problems, and bad feelings due to negative comments from others. Most relatives see treatment compliance as an important means of maintaining mental stability. They remind their members about the date of psychiatric follow-ups, put medication in a pill box, pay for the medication, take note of any mental changes and talk to psychiatrists. In a state of mental stability, a few individuals with the illness were tempted to quit medication. They did it and their parents got them back on medication.

5.3.2 Engaging in Daily Routine

Another common tactic used by persons with the illness to maintain their mental stability is establishing regularity in their lives. Most of them engage themselves in a daily structure to make their lives less boring or more constructive. They go to a certain place regularly to attend English-as-a-Second-Language classes, to do sheltered work, and to do volunteer work. Bill divides his day into different parts and forces himself to do something. He said:

> I go to the sheltered workshop for a few hours; I do not want to work in the afternoon and I build models and listen to music. It seems that I am competing with time to kill it. This is my present life goal. I fight with time every day until the evening at around ten o'clock. It is done and I can go to sleep. This is the happiest and most meaningful time of the day.

He is making tremendous effort to get his life going. Hon describes his routine as follows:

> I come to Hong Fook in the morning to attend ESL class and I walk around on the streets at 5:00 p.m. until the dinner time. I have my dinner outside and then go home. Every day is like that and I sometimes rent a video tape to watch at home.

Some relatives see that it is not good for the mental condition of their members with the illness to be idle. Mrs. Leung mentioned, "My son will not think so much if he has something to do." They assign house chores for their member with illness to do so as to energize them and to develop a sense of responsibility. They also motivate their members to go to a sheltered workshop, or to organized social activities.

> After I came home from the morning walk, I saw his shoes were gone and I knew that he had gone to a sheltered workshop. When I found his shoes there, I asked him why he did not go to work. He answered that he slept too long. I responded whether it would be a problem for going in late. He said that it was not a problem. I asked him to go as it would not be a problem. Because you are on medication, people will forgive you for sleeping late sometimes. (Mrs. Leung)

5.3.3 Reducing Stress

Maintaining mental stability means preventing relapse. In order to reduce the chance of relapse, some persons with schizophrenia have tried to manage the amount of stress that they can handle. A person with the illness attempts to go out to overcome his fear, and he sits at the corner of a coffee shop to make himself feel less stressed. He cannot handle so many tenants at home, so he hides himself in his room. Another one understands that she may not be able to handle the stress of gainful employment, and she prefers to stay at the sheltered workshop for the time being. Some participants get support from their relatives or mental health workers to manage their difficulties. Kwong said, "I sometimes am affected by many things such as the news, and I talk to my social worker." He felt less anxious after talking about them.

A number of relatives hold the belief that overstimulation will make their members sick. They protect their members from being over stimulated. They go along with their member's ways, help them to solve their problems (including financial supports), give advice to them on managing their stress, and keep some things secret from them.

> If any special, anxiety-inducing event happens, we do not let her know. Her father went into hospital, we did not let her go and said that her father had no problem. When she is anxious, she will think a lot. This kind of thing is not necessary for her to know. No need. She cannot help and asks anxiously about this and that, and we feel more burdened. (Mrs. So)

Relatives also provide a supportive environment to their members. They tried to be close and friendly to them, and be their companion.

> I want to be with her, and know how she is doing. She will not feel so lonely if she has a family and companion around. (Mrs. So)

With all the above coping strategies and support from their relatives, persons with the illness are able to maintain their mental condition as stable. This means that they do not relapse over a long period of time, but they may still experience symptoms and have very impaired functioning. However, most of them do not have much confidence about their future, and their relatives have expressed similar concerns.

5.3.4 Managing Concerns about Future

Regarding the future, some persons with the illness do not have a plan. One of them said, "I do not have any plan. How can I plan!" because she is still suffering from the persistent auditory symptoms. The other few expressed similar feelings.

> First I hope my illness can be fully recovered, but I learned from some friends that mental illness cannot be cured. I do not know about this, I hope my illness can be cured.

> When I am well, I can work and then I dare to plan for my future. (Hon)
>
> I have low opinion about myself with this illness, and I feel that I have a heavy dose of medication. I do not know how long I still be sick and when I can have a normal life. I heard that some people have been sick for ten and twenty years. It seems that there is no ending, and I dare not to know a girlfriend. (Bill)

Either they did not see that they can do anything for their future and avoid thinking about it, or they discussed their cure with their psychiatrist and are very cautious in trying things.

The other persons with the illness have a general idea of their future which is to have a job, and this is a usual expectation of an adult. However, they are not confident that they can work.

> I want to stand on my own feet, but the jobs outside this workshop must have certain demands as they give you pay….They will not have so little stress as the sheltered workshop. It will not be so good; therefore, I stay here though the pay is little. I am afraid that I cannot cope with the stress of outside work since they pay me more money. There is no such stress at sheltered workshop and the job is easy. (Nora)

They manage their incompetence with the strategies of: hoping to have a supportive employment, diverting to study, upgrading their vocational skills, waiting for opportunity to come or when they become more ready.

Most relatives are very much concerned about their members' future as they are getting old and they cannot be there for them for long. Mrs. Leung cried, "I do not know what will happen to him at the end." Their common worries are: whether the illness will continue to be stable, whether their members can be independent and can perform the social roles of work and marriage, whether government will continue to give financial assistance to their members in a climate of budget cuts.

> I do not know whether he will relapse. I went to the family support group, and they said that most of them will relapse. (Mrs. Ng)
>
> I worry about his inability to work. If there is no welfare from the government, it will be very hard for him. (Mrs. Ho)
>
> I worry what his future will be. Chinese traditional roles for an adult are to establish a family and to build up a career. He has the illness now, I do not know what his future will be. We cannot think about a solution for his future, we can only hope that he can recover early. (Mr. Lam)

> I dare not to think about the future, I will be unable to sleep if I think about it. (Mrs. So)

Relatives use active and passive strategies to manage their concerns. The passive coping includes living day-to-day, putting the problems aside, not thinking about them, letting the issues work out by themselves and creating hope that their members will get better or the government will take care of them. The active approach is to train their members to become more independent, to seek help from mental health workers and other family members, to look for a job for their members or to develop a small business for them to run, to encourage their member to try work, and to do whatever they can while they are still alive.

5.3.5 Coping with Emotions

Most persons with schizophrenia feel uncertain and powerless when their illness can be cured or when they can have a normal life of having work or family, and a few even feel depressed. They try to put these emotions aside, entrust in God, or divert their attention to something else.

> I let the illness take charge. I have no option. What can I do? The psychiatrist also has no answer. (Fong)

Some participants grieve over the loss of their capacities and have negative feelings about themselves, and said "I am garbage, a burden and cannot do anything." Some understand their limitations and their level of capacity, and try to develop themselves cautiously.

> I am slow in learning and at work. I cannot manage any job, I only can take those that are suitable for me. (Hon)

A few see themselves as normal and try to establish their personhood by distancing themselves from their illness.

Their relatives feel unhappy, gray and disappointed about their illness, and feel bad that they cannot have a peaceful retirement life. Some also feel stressful or burdened by performing the care giving role.

> I am unhappy. All other children have a good life and if he was not like this, I would be settled. Now, he makes me....(crying). (Mrs. Leung)

> The care for mental patients is pretty good here, he gets living allowance and shelter expense every month. This government assistance is for him alone. Though he is looked after, we are dragged....We cannot work as we take care of him...We worry where he

> sometimes has gone. When he has been out for long, we go out to look for him. (Mr. Lam)

Relatives try to manage their emotions by accepting their feelings, having their own lives, asking themselves to take it easy, putting aside the problems, listing the problems and solving them one by one, and getting help from professionals.

> I won't be pessimistic, and I am strong. When I have time, I ask people to play Majoan with me. I won't feel exhausted with the caring work. I am an active person. The party in our ESL class is organized by me. Our class goes out to have tea every month to celebrate birthdays for those who were born in the month....Our neighbourhood is very good. There are seventy to eighty people to do Tai Chi every morning. I leave home at 6:40 a.m. daily and come home at eight o'clock. I go to ESL class after breakfast. I attend two ESL classes. (Mrs. Leung)

In most cases, both the persons with the illness and their relatives do not talk about their emotions with one another. They either manage them by themselves or talk to professionals. This finding matches with the comment of Hsu (1985) that sharing of feelings is not a common practice in Chinese families.

In this stage of maintaining mental stability, most relatives also offer great support. They consider their member with the illness to be susceptible to stress and vulnerable to relapse, and continue to provide care to their members. They help their members to maintain the stability of the illness and worry about their future. Both relatives and their members with illness work hard to achieve the goal of stability. All persons with the illness succeed in maintaining their mental stability, but they struggle with how to perceive themselves and appreciate their capacities appropriately.

Persons with schizophrenia and their relatives are found to have different kinds of stress throughout the process of the illness. Relatives' stress is not significantly different from that mentioned in the literature review (Birchwood & Smith, 1987; Gidron, Guterman & Hartman, 1990; Johnson, 1990; Lefley,1987b). The financial burden of the illness on relatives in this study may not be a big issue as there is a largely free health care system and adequate financial assistance to persons with disabilities at this time in Toronto. Without such a social welfare system, relatives would have an extra burden on their existing financial constraints. The stress of their members with the illness is mostly related to the symptoms, side effects of medication, impaired functioning, and acceptance of the illness. Their experience and feelings are similar to those reviewed in the limited literature about stress that persons with mental illness have gone through (Hatfield & Lefley, 1993; Leete, 1987a; Lorencz, 1992).

There is a common finding of a high level of involvement by relatives among Chinese families in coping with mental illness all over the world (Lin, 1985); and this study finds the same result. This is attributed to the Asian cultural value of family as the basic unit of society, and a strong sense of family loyalty and obligation to take care of the sick member (Lin et al., 1978; Lin et al., 1982). Even now and here in Toronto, parents and other siblings in this study still hold the traditional Chinese value of family identity and a sense of obligation towards their member. Parents perceive that they have to take care of their children as best as they can until they die. When the parents have difficulties in performing their caregiving role due to various reasons such as a language barrier or lack of knowledge about resources, other children are involved whether they feel obligated or, become involved willingly.

The study finds that family members use a lot of self-directed coping strategies and seeking external help to manage schizophrenia. In spite of the great effort that persons with schizophrenia make to cope with the illness, they feel powerless at various points. They were overwhelmed by the symptoms at the onset, found themselves to be helpless with the persistent symptoms and feel uncertain about their cure. They dare not to have many plans for their future due to the limitations of their illness. Their relatives also have tried all available means to manage the illness and their emotions, they still cannot have a peace of mind at their old age, and have the unfinished business of worrying about the future of their sick members.

5.4 Summary

This study shows that families experience great stress from schizophrenia, and both persons with it and their relatives work hard to cope with it. The degree of relative involvement is found to be high and persistent throughout the course of the illness from discovery to maintenance. Relative support is noted in identifying the illness, linking up and following through with psychiatric treatment, seeking professional help to assist their members to re-establish their lives after first onset or discharge from hospital, and maintaining mental stability of their members. This high level of involvement by relatives reflects the emphasis of family in Chinese culture, and this indicates that it is crucial to study Chinese coping from a family perspective.

CHAPTER SIX

Family Interaction

As discussed in the previous chapter, there is generally a high degree of relative support throughout all the stages, but the degree of involvement varies among families. Some parents are very enmeshed with the illness while others are somewhat more distant. There are a number of reasons for the variation of involvement. Some of these are relatives' perceptions, their available resources, and their emotions. These differences lead to different types of interactions between persons with schizophrenia and their main care givers in the stage of maintaining stability as their needs for support change.

Persons with schizophrenia had a strong need for relatives' support in the stage of discovering the illness and linking to treatment. They relied on their relatives to identify their illness and to seek external help to manage their active symptoms. They also required tremendous support from their relatives in the stage of linking with treatment, particularly in overcoming their impaired functioning. At these stages, members' needs and relatives' support were complementary in most families. Only a few families experienced conflict, as their members did not have any insight into their illness and refused treatment, or they did not accept the illness at the same pace as their relatives and had problems in medication compliance. In the stage of maintaining stability, members with the illness have various responses towards their relative's involvement. They may react belligerently, seek help from their social workers to get more independence from their parents, manipulate the situation, pretend to be well, play the sick role, or appreciate the support. Their reaction reflects whether their relative's involvement matches their needs for assistance and independence. Three types of interaction have emerged in this study. The first type is problem free interaction, as relatives' degree of support matches their members' needs. The second is a feeling of burden from either party in the interaction, and the third is conflict/tension in the interaction. These different interactions will be discussed in this chapter.

6.1 Types of Interaction

Types of interaction here mainly refer to ways in which persons with illness and their main care giver perceive their interaction in times of mental stability. Their actual interactions in the past may have been cooperative or antagonistic in the previous stages.

6.1.1 Problem Free Interactions

Half of the participants with schizophrenia are to some degree independent. Some live quite independently on their own and basically take care of their own needs, while others contribute to some household chores at home. Most of them can decide what they want to do. A few need on-going emotional support from their relatives to understand their feelings of struggle. They are somewhat independent from their relatives in having their own social activities, though these are quite limited for some of them who spend most of their time in English-as-a-Second- Language class and at home. Others go to church or consumer-run social activities after sheltered work or part-time jobs.

For those who live rather independently, their relatives are least involved. They provide them primarily with emotional support through weekly visits or frequent contacts. Other parents are somewhat more involved. They remind their children with the illness to take medication, give them assurance and suggestions, and develop their sense of responsibility besides the emotional or financial support.

The involvement of these relatives matches their members' needs. The more independent members have the ability and willingness to take care of themselves with some support from an ethnic community mental health agency. The others prefer to have some more relative support. Therefore, the family relationships of these families are basically problem free and the persons with the illness respond positively to relatives' involvement.

> My relatives mostly worry about me. I hope my parents have long life. It is a blessing to have parents around. My mother sometimes does the dusting and I do not need to do it.

> Anything that she can do, she will do it. We do not have problems in relating with one another. My father sometimes comments on my not doing well enough. This is the only problem and nothing else. (Nora)

This type of mutually accepting relationship appears to have existed before the onset of the illness. Hon talked about the cohesiveness in his family:

> We stick together to face and overcome hardship. Just like when I was sick, my family was very supportive. When my family has difficulty, we all sit together to talk about it.

The strength of the family relationship is a resource for them when there is a stressor, such as the attack of mental illness on one of their members.

6.1.2 Feeling of Burden/Dependency in Interaction

Some participants with schizophrenia are more strongly dependent, and they rely on their relatives to take care of their daily living. A few have become able to concentrate on watching television and the others manage to do some assigned chores. One thinks that he can make his own decisions while others do not feel that they can or do not see that there is anything for them to decide. These participants are living with their family members, and do not have much of their own social life. One is doing a bit better. He goes to church in the company of his parents. His mother reported:

> Of course he does not know people in the church, and I speak for him most times. I briefly spoke to the person who gives him the ride to church, that Bill is passive and I hope that he can ask Bill into a cell group or activities. Therefore his church always calls him for activities. He sometimes goes, and at times doesn't. (Mrs. Leung)

Their relatives get involved a lot to help them such as giving advice about their readiness to work, feedback about their plans, looking after their daily living needs, accompanying them to face new challenges and helping them to solve problems. They also support their member emotionally and financially. One mother even has offered to get a business for her son to run. Members talked about their feelings towards their relative's support:

> I cannot make decisions for myself. I do not know whether it is because I am stupid. Since the day I was born, my father often told me how to do things. When I was in mainland China, my father was with me all the time and helped me to do things. My father has helped me since I was born.... My father helps me a lot. I would die without him here. (May)

> They help me a lot. My sister in Saskatchewan took care of me for two years. She helped me to apply for this and that. In Toronto, my mother took me to apply for welfare, and helped me a lot. I feel that I am a burden to them. If I were not alive, they would not have so much trouble. (Bill)

They appreciated their relatives' support. However, this created pressure on them which meant that they could not be open with their relatives. Bill knows that his mother is very concerned about him and he sometimes pretends that he is well to make her feel better. He said, "If they know more, they will become more worried. There is no point to get them worried." He finds no one in his family to talk to about his feelings. May tried to hide her feelings from her parent.

> If I tell my father that I am very troubled every time after I have been out with my separated husband, I cannot see my husband and he will be angry with me....My husband commented that I cannot make decisions and consult my father for everything. He said that I care a lot for my family and cannot make decisions.

She was caught up between her husband and father. She actually brought up her marriage issue with her social worker but told her father that her worker initiated the discussion.

In Lap's situation, he likes his parents to take care of him rather than having to do it himself with the insight that he is "lazy, a bit lazy." He said that his parents have never asked him to do house chores. His father reported that he feels burdened by taking care of him but dares not to tell him.

On the one hand, persons with the illness need to depend on their relatives to some degree due to their illness. On the other hand, their relative's high degree of support creates pressure and negative feelings about themselves, and reinforces their dependency. Relatives also feel burdened. In response to the situation, both parties are unable to communicate their feelings openly. Relatives are therefore unable to recognize their members' independence need. Hence, relatives frequently fail to adjust the degree of support that promote their members further growth. There is a non-match between what the members need and what their relatives do.

This type of dependent relationship seems to be developed prior to the onset of schizophrenia. Mr. Mak is very attentive to his daughter throughout her life; and Mrs. Leung helped her son to get a job, and used to live with him and his wife since he is the least academically advanced of all her children. The onset of schizophrenia probably made the dependence more profound.

6.1.3 Conflict/Tension in Interaction

A few persons with schizophrenia are very independent and competent. They make their own decisions and have ability in English to enable them to join vocational programs. They have the initiative to improve themselves. They have insight about the areas that need to be improved and are working on them. They would like to be more independent from their relatives but feel the pressure that their parents do not let them go. Kwong talked about the conflict with his parents over the housing issue:

> My mother did not allow me to move down to live in the basement. There are a bathroom and a kitchen in the basement. I would like to have my own place. My mother said that the basement was not good, she found it full of evil spirits, which may make me relapse if I live alone there. I talked to my social worker about it and she explained to my mother, then my mother agreed for me to move down to live in the basement.

He recalled why he lost his temper with his parents:

> I do not know why I was agitated in the past. At any time, if you talked to me, I disliked it. Maybe I was sick. I found them controlling and treating me like a kid. Therefore, I was agitated and spoke to them tersely.

Some relatives are quite involved, and their degree of support is not matched with their members' capabilities and need for independence. They appear to be overwhelmed by the vulnerability towards relapse and try to prevent it by giving more support than required. Moreover, the family relationship by itself is tense, and Kwong said:

> I did not shovel snow, and did not mow the lawn. I did not care. My sister commented to me about it, and I scolded her. She did not talk to me since then. She did not like my father and did not talk to him either. I guess that she did not talk to my father in Hong Kong already. They don't talk, not even a word.

The family tension developed before the onset of schizophrenia. It seemed that these families have communication problems and do not know how to deal with it. It is the mother who is the central person for communication in these families. As she is already burdened by the tension in the family, she is very anxious about her member's stability and tries to help.

Three types of family interaction are identified in this study, and the type of interaction reflects whether the relative's involvement matches with the needs for assistance and independence of their members, and existing family relationships (prior to the onset of the illness) which are accepting, depending, or tense. To analyze the interaction from the dimensions of the dependence/independence needs of persons with the illness and degree of involvement of their relatives is supported by Lefley (1987a). He viewed that the onset of schizophrenia impedes the development required for autonomous functioning, and a common problem in aged parent-adult child relationships is unresolved adolescent independence-dependency conflicts.

The dependency and conflict type of interactions are not healthy for both the parents and their members with the illness. Parents feel burdened and stressed while members may suffer from low self-esteem and may not actualize to their fullest potential. This finding is not new for social workers working with Chinese in the mental health field. My clinical experience reveals that most Chinese parents are protective and that this is their perception of caring. This can be perceived as controlling by their adult children and from a Western perspective. It is very hard for parents to draw a balance between care and letting go especially in a culture where the focus is on the family rather than on the individual, and on parents' authority rather than individual rights. In my opinion, they do not have the awareness, knowledge and skills to enable their members with mental illness to become more independent.

There is very limited literature about family interactions in managing schizophrenia. Most literature about family interactions focuses on how families cause the illness or adversely affect the course of the illness. The present study illustrates how families interact to cope with the illness particularly at the stage of maintaining mental stability and what the impacts are on both parties. The findings of types of interactions may give insight to parents, members with illness and to social workers. Parents may learn how to adjust their involvement in order to reduce dependency of their members with illness and to promote a positive self-concept. Members with schizophrenia may learn of the necessity to express their needs assertively and appropriately so as to develop control of their own futures to the highest degree possible. Social workers can learn of the importance of developing an effective intervention to enable both parties to establish a constructive relationship and to maximize the coping potentials in families.

6.2 Differences in Relatives

Types of interactions derive from different degree of relative support in managing the schizophrenia of their sick member. The differences may be attributed to relatives' perception of their sick members' capabilities and their care giving role, their views of mental illness and its recovery, available personal and family resources, and their emotions.

6.2.1 Perception of Members' Capacity

The functioning capacities of persons with schizophrenia tend to be significantly impaired at the onset of the illness, and are still limited at the stage of linking to treatment. The functioning is generally improved in the stage of maintaining stability. However, some parents do not think that their members can take care of themselves and do not feel comfortable letting their members be more independent.

> I find that she has not recovered in the area of handling things with organization and initiatives. She does not do things on her own and needs someone to ask her....Other than the routine of bathing her two daughters and doing their laundry, sweeping the floor and cleaning dishes, she does not do any other work. (Mr. Mak)
>
> You ask her to be independent, yet she does not know to take her medication and to dress properly. Her mental condition will gradually become worse, and no one will take care of her. She will be more lonely…..I remind her all the time. I live with her, it is natural that I remind her. If I let her live alone, how can I remind her? (Mrs. So)
>
> My son has strange behaviour. He does not want to contact people and classmates. Moreover, he told me that he could not memorize what he learned. He has the same problem in work, and he does not know how to do work. (Mr. Lam)

As these relatives perceive their members cannot take care of their own daily living needs and problems, they become involved frequently in their members' lives.

> I know that she will think about her problems all the time if they are not resolved….I wanted to stop her from continuing to think about her problems, so I went to see her social worker. (Mr. Mak)

Those relatives who regard their members with schizophrenia have achieved a degree of normality after receiving treatment tend to provide relatively less support.

6.2.2 Perception of Care Giving Role

Some parents perceive that they have great responsibility to care for their members with schizophrenia.

> It is my job, I gave birth to her. I have said if my daughter could not migrate to Canada, I would not be here. I would have stayed in Hong Kong to be with her until I die. I made up my mind. ...When I become sick and die, there will be no one to take care of her, and she will have to be independent. She eventually has to be on her own. However, if I have only one day left, I will accompany her. (Mrs. So)

These relatives mentioned that there will be no one to take care of their sick members if they do not do it, since their other children have to work and do not have time as well as do not know enough about mental illness. Mrs. Leung stated:

> No other way. If I do not help him now, no one will help him.

Mr. Lam stays home so as to take care of his son. He said:

> We often observe his changes in mental condition. If I go to work, I cannot stay on top of his situation and cannot take care of him.

This perception of their responsibilities seems to drive them to care a lot for their members with the illness.

6.2.3 Perception of Illness and Recovery

How relatives see what is conducive to recovery from the illness affects their degree of support. The conducive factors include: effective medical treatment, relative concern and support, and no adverse life events. Those few parents who see medical treatment as the only important element to one's recovery tend to be less involved with their children.

> The way to deal with her illness is to have psychiatric treatment. (Mrs. Fung)
>
> If my son continues to take medication which continues to be effective, he will not have problems and even be more normal than many people.... Other than that he continues to receive treatment and to study, we do not have much to give him. (Mr. Tam)

Most parents in this study who believe that social factors affect the mental stability of their members try to create a conducive environment or to prevent life stress for their members. Mr. Mak said that the most important thing is to protect his daughter from over-stimulation and Hon's brother described his view of recovery as:

> I think relatives are very important. You have to understand the patient. If relatives do not care about the patient, even medication could not help. We need to pay attention to him to know what he cannot accept....If relatives do not care about the sick member and do not know how to communicate with him/her, his/her illness will be affected.

These relatives have given a lot of support to their members throughout the stages, and they proceeded with caution when they wanted to train their members to be independent.

6.2.4 Emotions of Relatives

Relatives are uncertain about the prognosis of schizophrenia in their members, and are concerned that their members are susceptible to relapse.

> We do not know whether Kwong will ever be fully recovered. (Mrs. Ng)
>
> What affects me most at the present is Hon's future. We only hope that he will not relapse. (Mrs. Ho)

Relatives are anxious and try to prevent relapse of their member with illness.

> We need to see how to help Hon. We have to help if we want him to be better, because the psychiatrist only gives him medication. We do not expect him to be totally recovered as a normal person, but we do not want him to relapse. (Hon's brother)

This reflects why relative involvement is so persistent even at the stage of stability. A few parents have guilt feeling towards their members, and their guilt further increase their sense of responsibility in taking care for their members.

> I really wanted to leave when I saw the situation after my arrival in Canada. However, I could not leave, even now I cannot because of my daughter's condition. In her words, it is me who destroyed her. (Mr. Mak)

6.2.5 Available Family Resources

Family resources include health and available time of parents, their sense of competence, the financial condition of families, and support from siblings. The health of all participant parents is generally good, and they have time to take their members around if required. Mrs. Leung said, "When he first came back to Toronto, I accompanied him where ever he went."

Some parents feel competent about themselves in terms of knowledge, personality and previous successful life experiences. This sense of competence helps them to cope with the illness, to manage their own emotions and to deal with the social stigma attached to mental illness.

> I am a person with integrity and people respect me. Our family is not wealthy but we are well behaved. We do not borrow money from people and do not indulge in gambling. Our family is well behaved. My daughter has illness and it is the illness, not her own character at fault. (Mrs. So)

Parents with better financial situations are able to help their members more. For instance, Mr. and Mrs. So are paying for their daughter's medication so as to promote her compliance, and they are able to afford a spacious house to allow her to have her own physical space. Lack of physical space creates stress for some members with schizophrenia. Financial tightness poses difficulty for relatives. Mr. Lam stated clearly that they could have more energy to take care of their son if their financial constraints could be eased by approval of their application for subsidized housing.

Most parents have support from other children. Some children provide financial support and some get directly involved to help the parents to manage the illness of their siblings. Some siblings took up the role as main care givers while their parents were away. A few families are very cohesive and have a strong sense of togetherness. This is a resource allowing parents to better cope with the illness. Without the help of other children, a few families would not be able to manage the illness.

> It is good to have the daughters to help....otherwise it would be bad since we did not know much. (Mrs. Ng)

A few relatives who have few resources and are caught up with their own problems appear to be less involved. One mother cannot do much to help her daughter (whom is not welcomed by her son's family) because she herself has to rely on them. Her other daughter has limited resources to offer as she is unemployed. Another parent struggles with his own emotional issue of not having had a job since his immigration to Canada, and appears to be more detached from his son's illness.

In addition to the general Chinese cultural influence of the importance of family identity and a sense of obligation towards their members, relatives have different perceptions, resources and emotions which shape their degree of involvement.

6.3 Summary

There is a high degree of relative support in managing schizophrenia. However, there are differences among relatives which are attributed to their perceptions of the impairment of their members and of their care giving role, their meaning attached to mental illness and its recovery, their emotions and the available family resources. Their members with illness respond differently to their involvement and form different types of interactions with their main care giver depending on their need for assistance and independence. There are very limited studies on how families interact to cope with the illness. This study indicates that there are three types of interaction in the stage of maintaining stability: problem free interaction, feeling of dependency/burden in interaction, and conflict/tension in interaction. Their interaction is also shown to be a continuation of their family relations prior to the onset of the illness. This finding implies that some parents need to reduce their involvement with their members with schizophrenia, and some individuals with the illness need to learn how to express their needs and to assume responsibility. There is a need for social work intervention to enable both parties to communicate their emotions more effectively.

CHAPTER SEVEN

Supports And Barriers In Coping

In the process of coping with schizophrenia, there are both supports and barriers for relatives and their members with the illness. The supports include the formal support provided by health care and social services, while the informal supports come from religious affiliation and friends. Barriers to coping are the social stigma attached to mental illness and families' lack of cultural and social resources as new immigrants.

7.1 Support

7.1.1 Formal Social Support

Formal supports provide different kinds of services to both persons with schizophrenia to enable them to live in the community, and support to their relatives in managing the impact of the illness. Without these supports, both persons with the illness and their relatives would face insurmountable difficulties in managing schizophrenia.

7.1.1.1 Mental Health Care Services

Mental health care services provide several kinds of support to persons with schizophrenia and their relatives. Their primary treatment modality is that of pharmacotherapy. Hospital care also provides remedial treatment for acute psychotic episodes and community psychiatric follow-up monitors the patient's on-going mental condition. Studies have shown the efficacy of anti-psychotic medication for treatment of schizophrenia (Davis & Gierl, 1984). Most interviewees with the illness reported that while under mental health care, their mental condition remains stable and their relatives have similar views. One person with the illness even reported that medication was the most helpful to him among all types of support.

With one exception, all participants with the illness have been hospitalized for psychiatric problems. Five persons were hospitalized once only, one had two hospital records, while the last one had eight to ten hospitalizations. Their length of stay ranged from a few days to almost six months. The reasons for admission to hospital were active psychotic symptoms such as hallucinations, delusions, suicidal ideas or attempts, and aggressive or strange behaviour (i.e. standing against the wall without food or sleep for days). Hospitalization usually occurred at the early stage of their illness when they were initially linked with psychiatric treatment. For the two people who were hospitalized more than once, their latest admissions were within the previous two years of the interviews.

Hospitalization is very useful for them to control their acute psychotic symptoms. Kwong reported, "A nurse gave me an injection, after which I felt very quiet." Hospital is also perceived as a shelter. Bill said:

> When I was in hospital, I felt I was a real patient, as I did not need to think about my future or look for jobs. There was no need for me to worry about this and that.

The study of Lord et al. (1987) found that patients reported varied experience with hospitalization: a refuge, help, or a demoralizing experience. Participants of the present study also recall differing experiences with hospitals. Tak complained that his nurse pretended to be a ghost to scare him, to take his false eye out, and restrained his hand with the excuse that he might poke out his other eye. He felt intimidated and powerless in a psychiatric institute. Kwong had a positive experience with hospital staff. He said, "The doctor explained to me that I was sick and had hallucinations, and also that was why I heard voices."

After discharge from hospital, persons with schizophrenia are followed up by a psychiatrist in the community or at the outpatient clinic of hospitals. Possibly due to the limited number of Chinese psychiatrists in Toronto, all participants (except the one who was recently referred to be monitored by a general physician) are seeing the same two psychiatrists. They report having good communications with their psychiatrists and talk about various issues. They reported on their mental condition, gave feedback about any side effects, asked about the prognosis of their illness and when medication could be stopped. They also talked about their sleeping problems, fear, and other emotions. Their psychiatrists gave them suggestions such as going to structured programs and advice on how to manage their fear, plus instructions on the side effects of medication, and how to deal with problem relationships, as well as simply prescribing medications. However, a few found that their psychiatrists have so many patients and they felt time pressure during interviews. In response, they prepared in advance what they wanted to tell their psychiatrists or tried to manage their condition if possible by themselves.

Studies showed that caregivers felt frustrated as they had not been included by mental health professionals, and their needs for knowledge and skills were not recognized (Marsh, 1992). However, caregivers in this study report different views. They sometimes go with their members to see the psychiatrists to talk about their concerns such as prognosis, medication, housing, and marital problems. Most reported that their needs are being addressed. Mrs. So, for example, said that the psychiatrist taught her to buy a pill box for supervising her daughter's medication. This discrepancy may lie in the fact that the two psychiatrists come from the same ethnic group as the persons with the illness and their relatives. Thus, they may understand the importance of including relatives in treatment of Chinese patients.

The effective communication between psychiatrists and families facilitates having a better understanding of the illness, and maximizes the effects of drug treatment while minimizing the side effects of the medication.

7.1.1.2 Social Services

Medication only helps symptom reduction. Persons with schizophrenia need social services to help them to reestablish their lives, which were seriously disrupted with the onset of their illness. They have used a number of social services such as an ethnic community mental health agency, government financial assistance, affordable housing, vocational services, social recreational programs, and others (children's aid society, home care and police service).

All persons with schizophrenia in this study have used or are using the case management services of an ethnic community mental health agency (through which they were recruited for this study). This service is considered an essential component of community support (Anthony & Nemec, 1984). It tries to help clients gain access to different services while following them to ensure continuity. It also coordinates services to meet their multiple needs. Case Management is listed as one of the priority services in the mental health reform of Ontario. For a new immigrant with schizophrenia and limited English, it is particularly important to have a case manager to help them access their required services, as these are very fragmented in Ontario. Persons with schizophrenia in this study found the case management service helpful to link them up with various services and coordinate these services for them. They benefit from its counseling and its work with their relatives, which includes education and mediating family relations. Bill imagined that the consequence of his life without this support was that he might stay home all day and continue to be isolated. Kwong remarked that:

> It helped me to contact the external world and bought me to see the outside world. I had the chance to contact other people.

Mosher (1986) stated that the working relationship of the case manager and his/her clients is peer-like rather than parent-like, and thus the client will take more initiative to control their own lives. A hierarchical relationship still can exist in case management services; it depends on the approach of the individual case manager and expectations of clients. Persons with the illness and their parents generally regard case managers as someone with knowledge, and treat them as a resource person or consultant.

Relatives benefit from the ethnic community mental health agency both directly and indirectly. When their members gradually re-established their lives with support, relatives' lives became less stressful. They said:

> His illness has been maintained quite well due a lot to Ms. Tang's help. She assisted him to get out of the house. He slept all day in the past and I did not know what to do. (Mrs. Ng)
>
> He knew more friends. He had someone to talk to in the class, and became more open. There were activities to engage him, and he would not think about other things. (Hon's brother)

The study of Reinhard (1994) demonstrated that professional support helps to reduce the objective burden of relatives through practical advice and enhancing personal control. Relatives got direct support from the service through a family support group or individual contact with a case manager. Mrs. Ng said that the family support group helped her learn about mental illness. Mr. Mak commented:

> I find the most useful service is from Ms. Sin at the ethnic community mental health agency. She helped me with whatever questions I have....I could not manage without the help from Ms. Sin.

Government financial assistance is important to persons with schizophrenia. It provides them the basic living and medical expenses which give them and their relatives a sense of financial security. Mrs. Leung said:

> I asked his psychiatrist whether Bill could quit this pill. He answered that Bill can take another one but it is more costly. It costs a hundred dollars and he did not have a drug card at that time. He was anxious about medical expenses. Now, he does not need to pay medical expenses. I found him to have become more relaxed after he got government financial assistance.

Some participants are living in Metropolitan Toronto Housing Authority (M.T.H.A. - rent geared to income) housing on their own or with their families, but none of them live in a group home situation. A few had lived in different places before settling down with metro housing. Mr. Mak appreciated that they got metro housing with help from social workers. Mr. Lam defines low cost housing as their first priority now and he explained:

> I can take better care of him, he can concentrate on his recovery and his brother will not be disturbed by him.

It shows that affordable permanent housing is essential to some persons with the illness and their relatives.

Attendance in structured programs is conducive to the rehabilitation of persons with schizophrenia (Cotterill, 1994). In this study, the programs that most persons with the illness join are sheltered workshops, vocational programs, and English-as-a-Second-Language classes. These activities provide a routine for them and are a social connection with others. Participants have different feelings about their programs.

A few are working in a sheltered workshop, and their comments about it are quite varied. Nora feels content with the sheltered work, as she may not be able to handle the pressure of gainful employment, while Bill feels stressed and reported:

> They treat us as workers rather than patients, and as robots to hurry up with work. At first, I thought that this workshop is for patients and should be quite relaxing. They gave us pressure and I give out so much labor, and only get back $1.75 per hour. It is unfair. It is fine to give me that amount if they treat me as a patient.

However, the workshop provides a place for him to socialize with others. He said that he shares with other clients at the workshop information about medication, illness and community resources.

A few had very positive experience of participating in a vocational programs which provides computer training, development of office skills, and work experience through placement. Kwong found the program brought about a positive change in him, and he talked about his placement experience:

> After two to three weeks, I began to feel that the white people treat me very well. I started to talk more with the co-workers who were female and quite nice. I began to chat with people and felt good.

As they are found to be vulnerable to extremes of social stimulation (Cotterill, 1994; Strauss et al., 1987), persons with schizophrenia require that these structural programs are most beneficial if they are designed to meet differing levels of social functioning. Inactivity or under-stimulation will exacerbate negative symptoms and over-stimulation may precipitate relapse. When the programs met with their capacities, the experiences empowered people with the illness to develop a positive image of themselves and thus helped their recovery. Given this requirement for varied levels of stimulation, the diversity of structured programs in Toronto is inadequate to meet different levels of needs. Other than learning English, a number of participants with the illness go to English-as-a-Second-Language Classes for the purpose of filling their time. It is also a program that they can join with limited English ability.

Severe limitations in choice present an experience of powerlessness, which is a deterrent to one's recovery. In a time of budget cuts, it is very hard to obtain funding from governments to develop new programs to provide work opportunities and social contacts in accordance with varying functioning and language levels. As these experiences are virtually a necessity in building a positive self-concept, (which in turn promotes recovery), it is of critical importance to the long-term wellness of those who suffer from schizophrenia to have such programs available. Mobilization of greater resources within the community may be called for. Relatives' burden is reduced as their members' condition is improved with formal support and they get practical advice from the professionals.

7.1.2 Informal Social Support

Other than professional support, personal networking with religious institutions and friends constitutes a buffer to the stress of coping with schizophrenia. Worshipping ancestors and god is a way for a few relatives to handle the illness of their member at the discovery stage. Church also serves the functions of providing a place to spend one's time and a source of emotional support for a few persons with the illness:

> I feel delighted after reading the Bible and going to church....We go out for tea after gathering and each pay a few dollars. It is God's leading. My church is good. Though it is small, most time people are concerned about each other. (Nora)

In terms of support from friends, most persons with schizophrenia report that they had very limited social circles while their relatives are found to have sufficient friends to meet their needs. Relatives obtained information about community resources to assist their members with treatment, received practical help such as accommodation and rides, and had social lives with friends as a release from the burden of managing the illness.

Most persons with the illness have no friends. Their difficulties limit their ability to travel around on their own. They may lack social skills, and have a limited social circle. A few of them only manage to go to one or two places, usually where they attend programs and see their psychiatrists. They talked about their difficulties in making friends as:

> I have known quite a number of friends who have mental illness. Because of our illness, we can't get along well and eventually fall apart. I also know a few friends who are not so sick, they progress very well and I envy them too. They seldom came back to mix with our patients with mental illness. They have been rehabilitated. Some have married, and

> some have their own career. I do not know many friends outside. I am not sure whether that relates with my mental illness. Maybe my life circle is small, and thus I know few friends. I mainly hang around a community mental health center and a consumer-run social center, and do not have opportunity to know friends outside. (Hon)

Nora explained why she had not wanted to mix with people having mental illness and how she changed her attitude:

> I had a perception in the past. Regardless of people who look down upon us with this illness, I at times looked down on myself! For example, I did not join the activities organized by the community mental health center or consumer-run social center. I thought that those people were bad apples. None of them were good and what was the point of going. I have changed this perception now. I should not think this way. If you do not even have them as your friends, where are you going to get friends? It is kind of looking down upon people. However, I joined a few times and felt better about them. I should not have this thinking because they sometimes know how to help each other. For instance someone prepared the food, and someone arranged the entertainment. They all contributed their efforts, and I should not see them as bad apples.

It appears that their illness jeopardizes their ability to socialize. The negative labeling of mental illness made them hesitate to mix with people in their circle, and their limited life circles posed difficulties for them to know someone outside their group. They experienced severe hardship in developing friendships.

This phenomenon of an inadequate social network is well documented in the literature (Morrison & Bellack, 1984). Studies of persons with schizophrenia living in the community reported that 75% are described as very isolated or moderately isolated (Torrey, 1988). The study of Estroff & Zimmer (1994) showed that individuals with schizophrenia were more likely to live with their family and had smaller networks which were more heavily concentrated among kin than those of any other diagnostic group. Investigation suggested that symptomatology and hospitalization influence the social network (Estroff & Zimmer, 1994). The stigma of mental illness is also viewed as a contributing factor; persons with mental illness are uncertain about others' response towards them and may withdraw from social contacts (Link et al., 1987; Torrey, 1988).

7.2 Barriers

Chinese families in this study experience double barriers in their coping. One is the general social stigma attached to mental illness and the other is the vulnerabilities of new ethnic immigrants.

7.2.1 Social Stigma

The social stigma of mental illness has been demonstrated to be held across various groups of people (Skinner et al., 1995). It has been one of the greatest obstacles for people with mental illness (Leete, 1992; The Mad Hatters, 1992). Relatives and members with schizophrenia in this study believe that Chinese hold a stigma towards mental illness and the persons with it. They explained that Chinese generalize that all people with mental illness are aggressive and do not have control of themselves, and thus are afraid of them and reject them.

> I think that generally people will like you when you are prosperous. There are very few people who will care about you when you are in adverse conditions, especially towards sick persons. You are mentally ill, they will be afraid that you are aggressive. If you have another illness, they will be afraid that you are contagious. People in general have prejudice against patients unless the patient is our own family member. (Mr. Lam)
>
> Mentally ill people may become naked or misbehave sexually when they are seriously sick and thus people look at them differently. (Mr. Mak)
>
> Some of them do not look smart, and sometimes do not look clean. People thus have an generalized impression that all persons with mental illness are like these….Some persons with mental illness cannot take good care of themselves and their appearance are not good. They are mostly being looked down upon. (Nora)

They bought up the issue of the determinant factor of social stigma. A number of studies have inquired whether the behaviours or the acquired label has a greater effect on the acceptance of people with mental illness. The study of Link et al. (1987) showed that people do not simply form an evaluation based on behaviours or labels. Rather their pre-existing beliefs about mental illness affect their level of acceptance. Those who believe that persons with mental illness are dangerous are more likely to reject a labeled person.

The rejecting social attitude towards the mentally ill poses difficulties for both relatives and their members. The difficulties include social problems in housing, marriage and social relations, and subjective sufferings and diminished self-esteem (Hatfield & Lefley, 1993; Page & Day, 1990). Participants in the present study reported:

> We are renting this place, and do not know when the landlord will kick us out. We hide from the landlord about my son's schizophrenia....If the landlord does not rent the place to us, we will be in trouble as s/he spreads around the news that my son has mental illness and no one will rent to us. (Mr. Lam)
>
> I have pressure to see my psychiatrist. I am afraid that people see me going in and say that I have mental illness.... People see me going to mental hospital and no one dares to be close to me. Every person looks at you, and Chinese are like that. (Tak)

Bill expressed that he looks down upon himself and therefore he will not feel bad about others' rejection towards him. His low opinion about himself may affect his recovery.

Link, Cullen, Mirotznik, and Struening (1992) viewed that persons with mental illness may impair their ability to function with the internalization of social stigma. The expectation of being rejected is a self-fulfilling prophecy (Hatfield & Lefley, 1993). When they expect that people will reject them, they feel threatened by the interaction with others and thus affect their performance. The study of Link et al. (1992) showed that the degree to which a person expects to be rejected is associated with demoralization, income loss, and unemployment in individuals labeled mentally ill.

Relatives also internalize the social stigma and have similar fears and shame towards the illness themselves as do other people. Mr. and Mrs. Lam said:

> We feared that our son became aggressive suddenly as he did not know what he was doing, and we hid the knife from him every night.

Some parents have handled their own feelings towards the illness. Yet other family members still feel shameful at having a member with mental illness. Mr. Mak reported the worry of his son that no one will marry him because of having a mentally ill sister. Mrs. So stated:

> My other children do not live with her. If they did, they would not invite friends home.... She has a strange behaviour of interrogating people all the time. She is very eager to know friends and when she meets someone new, she asks people where they are living and what their telephone number is. Her presentation makes people know right away that she has a mental illness.

The negative attitude towards disability, objective discrimination and subjective self-stigmatization, all make the process of accepting the illness more difficult. Relatives are more able to accept the illness with different strategies, and their members experienced a longer process. After being diagnosed with schizophrenia, some of their members tried to accept their illness with an explanation and a few used denial and avoidance (they stayed at home all the time and refused treatment). Most eventually come to an acceptance of their illness, and identify themselves as a special group and assume patient status. Patient status has different meanings for persons with schizophrenia: dependency or hard work. Some do not think that they have abilities to do much. A few pay attention to their appearance, assert their rights as persons, and make themselves useful to others.

> People choose me in mate selection and I choose them too. People have a right to choose me, why do I not have the right to choose them and look down on myself so low. (Nora)

> I hope the community knows about mental illness, and will not have fear towards us. The general public thinks that mental patients are violent, and avoid us. We are not so fearsome, and just people who can also have rational thinking. (Hon)

7.2.2 Immigration

There are numerous demands for immigrants to settle in a new country. Their challenges include novelty, and changes in physical, social and cultural environment (Baker, 1993). These demands will be more salient with schizophrenia in a family. All participants in this study, both the parents and their members, are first generation immigrants to Canada. In managing the illness, relatives reported that the vulnerabilities of being a new immigrant pose barriers for them. Vulnerabilities include inadequate information about community's resources or how the systems of a new country works, language problems and unfamiliarity with the physical environment.

Lack of knowledge of social services is often cited as a major factor for underuse of social service among the immigrant population (Christensen, 1986). With the pressure of schizophrenia, relatives were in great need for services and experienced frustration in looking for them. Some relatives felt great stress at the beginning of the illness as they did not know where to get help and their members were getting worse.

> I had been here for less than two years when I first found the illness of my daughter . I was not familiar with the social welfare here and did not know that there was an ethnic mental health agency to handle my daughter's problem. (Mr. Mak)
>
> New immigrants need to get someone to help. We were blind in the new environment, and even did not know how to look for a doctor. (Mrs. So)

Some relatives did not know how the social service system worked and asked:

> Is there any money that I need to pay? I do not know. There may be something that cannot be spoken out or cannot be known by others. (Mr. Lam)

The language barrier is another problem for families in dealing with various government departments. They have to depend on someone to do the translation for them. The language limitation also jeopardizes relatives' ability in coping with the illness.

> I do not know about this new environment. If I were in mainland China, I would not be afraid as I knew everything well. My working ability and life experiences enabled me to sort out problems. Having been here, I do not have the language to communicate and it is a big problem. No matter big or small issues, I cannot speak and have no use. (Mr. Mak)

Language barrier limits the choice of programs for persons with the illness. They have to have some degree of English before they can attend any mainstream program. This is the reason why most of them are either in the English-as-a-Second-Language classes or staying at home. Limitation in English also affects one's ability to express oneself and this limits their social relations. The worst barrier of all is inability to communicate with one's psychiatrist in English.

> I did not know the effects of my medication and even what kind of mental illness I was having. If I asked her/him, I could not understand what s/he answered. (Bill)

Some relatives also needed to learn to travel around in the new environment to take their members with illness to various service agencies. They are proud when they manage to learn the way to places.

Families are in need of social services to enable them to manage the illness but the lack of knowledge of social services and the language problem make it difficult to get access to the required services. The ethnic community mental health agency plays an essential role in helping this particular group of immigrants.

7.3 Summary

Schizophrenia has a great impact on the person with it and their relatives. Families afflicted try their best to cope but cannot manage without social support. Health care provides psychiatric treatment to persons with the illness to control their symptoms to allow them to function in the community. They require social services to support them to live in the community with their needs of finance, affordable housing, vocation, and social relations being met. Appropriate rehabilitation service to their functioning is found to be very beneficial to their recovery from the illness. However, there is inadequate service to cater to various needs of persons with different functioning levels especially in a time of budget cuts. Without support from existing available services, relatives would have great difficulties to cope with schizophrenia of their members who are likely stuck at home without treatment.

Other resources such as religion and friends also enable families to cope with the illness, and they need help in further developing these assets, especially for their members with illness who have a limited social network. However, the coping capacities of families are limited by social stigma and vulnerabilities of immigrants.

CHAPTER EIGHT

Conclusion

8.1 Discussion and Summary

The purpose of this study is to know what Chinese families have done to cope with schizophrenia and to explore what will enable them to cope better. In particular, I focus on the interaction between individuals with the illness and their relatives so as to review the shift from a polarized conceptualization of either relatives' or consumers' perspective to an inclusive conceptualization incorporating both perspectives. References to the cultural background of the families interviewed is also made. One of the major findings of this study illustrates that persons with schizophrenia and their relatives try their best to cope with the illness. Their coping strategies include self-reliance, family-reliance and seeking external help. The role that relatives play is extremely important in the coping processes in Chinese families.

8.1.1 High Degree of Relative Support

Schizophrenia poses continuous stress for both persons with it and their relatives. In coping with the illness, three stages evolve: discovering the illness, linking with treatment, and maintaining stability of the illness.

In the stage of discovery, some of the persons with schizophrenia were aware of the changes in themselves and tried to manage with self-directed coping strategies such as tolerance and rationalizing their problems. When they found themselves unable to deal with their increasingly overwhelming symptoms, they turned to their relatives for help. For those who were not aware of their own changes, their relatives noticed their differences. Relatives did not recognize those changes as psychiatric problems at the beginning and tried to manage any problems within the family. Once the situation became more serious or obviously a psychiatric problem, they sought external help primarily from the medical profession.

Lin, Inui, Kleinman, and Womack (1982) argued that the delay in help-seeking was due to the stigma of mental illness and Cheung (1987) suggested that poor understanding of psychiatric problem and low awareness of psychiatric services delayed the approach to professional resources. In this study, the lack of knowledge about mental illness was identified as the main reason for the delay, and the first entry to professional help was through the family physician. Lin, Tardiff, Donetz, and Goresky (1978) indicated in their study that the family physician was contacted when external assistance was sought because the behaviour disorders were seen as having a physical etiology. Cheung's study (1987) agreed that the pattern of help-seeking of Chinese psychiatric patients was related to their conceptualization of the problems. Most families in this study viewed that the illness has a psycho-social origin. The medical consultation may relate to the lack of differentiation between mind and body among Chinese and the availability of family physicians.

All persons with schizophrenia in this study became linked up with treatment with the help of their relatives. These consisted of both parents and siblings in more than half of the families. Siblings were more involved in this stage because the parents had limited knowledge of community resources and English to connect with services, and some of the parents did not have the basic competence to deal with the situation. This reliance on relatives in help-seeking among Chinese psychiatric patients was also found in other studies (Cheung, 1992; Lin et al., 1978; Lin et al., 1982).

After linking with treatment, persons with the illness struggled with the persistent symptoms, side-effects of medication, their impaired social functioning, and re-establishment of their lives. They tried to manage these with different means such as endurance, accepting their limitations, letting the illness take charge, consulting their psychiatrist, accepting help from community mental health agencies, and obtaining support from their relatives. Their relatives gave them all kinds of emotional and instrumental support to assist them through their difficulties. Some relatives equipped themselves with more knowledge and skills to carrying out their supportive role through reading, attending workshops and consulting professionals.

At this stage, most individuals with the illness tried to accept their illness as it occurred or explained it away with fate, accident or social isolation. A few had problems accepting it, they tried to deal by denial or becoming depressed. Relatives tried various ways to deal with their members' negative response towards the illness, and got help from other children or community services. At the same time, they helped themselves to accept the illness by comparing their members with more serious cases, sustaining optimism about possible recovery, focusing on the positive progress of their members, thinking that they were not alone, telling themselves that it was not shameful, and channeling their emotions into problem solving.

Relatives' involvement continues even when their members are mentally stable, as they consider that their members are susceptible to stress, and thus vulnerable to relapses. They keep on reminding the ill members about medication, and try to create a stress free environment for them by going along with their ways, solving problems for them, and keeping some things secret from them. They also facilitated the rehabilitation of their members by developing their sense of responsibility and supporting them in engaging in social activities and structured programs. Most persons with the illness recognize the importance of having a routine and try to become involved in structured activities. To maintain their mental stability, they monitor their medication and psychiatric follow-ups, and regulate the amount of stress that they can handle. Regarding the future, both persons with schizophrenia and their parents did not think that they can have a plan. They cope with the uncertainty of the future with either putting it aside or having hope that something will work out.

The study finds that families use a lot of personal and family resources such as endurance, self-control, determination, diversion, caution, acceptance, putting the problem aside, having hope, keeping things secret, and getting help from other family members. The parents use additional tactics of getting along with their members' ways, providing practical support and solving problems for them. Families frequently adopt the philosophy of doing nothing, for instance, letting the illness take charge, accepting the illness as it occurs, waiting for opportunity, and letting the problem work itself out. This passive approach in dealing with problems can be due to the influence of Toaist philosophy among Chinese and their belief in external locus of control. As self-directed and family-reliance coping are the major coping strategies, stronger emphasis on developing families' coping skills will enhance their problem-solving abilities.

Families also seek help from social services because schizophrenia is a serious illness which requires that they have to rely on external support. This study shows that there are different needs for families at different stages of coping. Both the persons with the illness and their relatives (particularly the parents) have tried their best to cope with schizophrenia. They work towards the same general goal of minimizing the impact of the illness. However, undesirable relationships, dependency and conflict, are also identified particularly at the stage of maintaining stability. These issues will be discussed in the following section which deals with the interaction between persons with schizophrenia and their relatives (who are primarily parents).

8.1.2 Interaction

At the stage of discovering, persons with the illness relied on their relatives to help them to manage the illness, and most of them were cooperative with their relatives. A few however refused to accept treatment due to lack of insight into their illness, or lower levels of compliance with relatives in times of acute symptoms.

After linking to treatment, most persons with the illness became more able to manage the impact of the illness with enormous support from their relatives. Most families worked together to cope with the illness. A few relatives and their members accepted the illness at a different pace, and they were unable to communicate each other's concerns and experienced conflict over medication compliance.

At the stage of maintaining stability, the interactions of the persons with the illness and their relatives are different from those in the previous two stages. There seems to be three types of interactions, namely problem free, dependent and conflict. The different types reflect whether relative involvement matches with the need for independence of their members.

In the problem free interactions, members with the illness are to some degree independent in the areas of daily living, decision making, social lives and living arrangements. They report the level of involvement of their relatives matches with their needs, and appreciate the type of relative support. Half of the families fall into this category.

In the dependent type of interaction, persons with the illness have greater functional impairment and their relatives get involved a lot to help them. As a consequence, members with schizophrenia have a poor opinion of themselves while the parents feel burdened. In order to make the other party feel better, they try to hide their feelings. The persons with the illness either desire to have greater control with their situations and to become more capable, or they recognize and accept their laziness. What they need is an environment that facilitates their trying out their potentials. However, their parents do not have the insight, knowledge and skills to help them develop towards independence because of the lack of appropriate support. There is a mismatch between what the members need and what the relatives provide. This type of interaction will adversely affect the burden of parents, and the recovery of persons with schizophrenia as they tend to have problems developing a positive self-concept. James Howe, former president of the National Alliance for the Mentally Ill, has similar concerns. He stated that the care-giving role was detrimental to aging parents with their diminishing energy resources, to other children still living at home, and to the potential independent functioning of the member with the illness (cited in Lefley, 1987a, p. 1064). The advice of simply being non-involved is not helpful to both parties either, and works against the Chinese cultural norm of family obligations. A more effective intervention to attempt to enable both parties to change in making their relationship more constructive is required.

In a conflict/tension type of interaction, relatives are still involved a lot though their members are quite capable. Members feel that they are being controlled and do not know how to deal with it. They sometimes expressed their emotions with anger towards their relatives.

The differences in relative involvement in these three types of interactions do not seem to be related to the actual impairment of the ill members. The explanation may be: relatives' perception of their members' capabilities, the meaning that they attach to their care giving role, their views about recovery, available personal and family resources, and their emotions. For the problem free interactions, parents believed that medication is important for recovery, and are more able to recognize the capacities and the independence needs of their members as well as their limitations in providing indefinite support due to their age.

This study seeks to provide new knowledge of how persons with schizophrenia interact with their relatives in coping with the illness especially at the stage of maintaining the illness, and how their recoveries are affected by different types of relationships. It also helps develop insight into the possible reasons for different types of interactions. This study points out the importance of having a dual perspective in developing interventions to maximize the coping potentials in families.

8.1.3 Support and Barrier

Schizophrenia is a long term illness which can disable a person considerably and cannot be managed solely by the resources within a family, thus persons with it have complex long term health care and social services needs. This study indicates that persons with schizophrenia have some of their needs met with the existing services in Toronto.

Most families find the mental health care services helpful. They appear to have effective communication with their Chinese psychiatrists in the community, and relatives feel good about being involved in the treatment of their members. They still complained about the long waiting list and unavailability of Chinese psychiatrists in their neighbourhood. However, research on needs of relatives showed general dissatisfaction with mental health professionals (Francell et al., 1988; Lefley, 1989). The difference is that relatives in this study are mostly dealing with Chinese psychiatrists and the staff of a community mental health agency which specifically recognize the importance in the Chinese culture of including relatives, and thus consciously or by chance meet the needs of relatives.

Families appreciate the assistance that they get from an ethic community mental health agency as they have limited English and knowledge to approach the scattered social services in Toronto. The case management service has linked up their members with required services and provides a long term support to them. The kind of programs that their members can get into depends on their language skills and level of functioning. There are very few agencies which have staff who speak Chinese, and limited types of programs to cater the different functioning levels of their members. Most persons with illness in this study spent their time at home, at an E.S.L. class or in a sheltered workshop.

One of the major handicaps of persons with schizophrenia in this study is social inadequacy, and it is a well documented problem in the literature (Caton, 1984). The persons with schizophrenia in the present study reported that social inadequacy is one reason for their limited social circle. It appears that a number of them would like to have more friends, and their relatives also support them in developing larger social networks. Some persons with the illness attended a consumer-run self help center, churches and a befriending program. For others, the inability to travel on his/her own and low self-esteem are the other barriers that restrict their social activities. Other studies suggested that symptomatology and the amount of time spent in hospitals influence the social network size of schizophrenic persons (Estroff & Zimmer, 1994). Social network is shown to be helpful as the increase in network size of persons with psychiatric illness was linked to better mental health (Cotterill, 1994; Lord, Schnarr & Hutchison, 1987). Their social connections are also related to a lower burden on their relatives (Crotty & Kulys, 1986). The problem of social inadequacy is fully recognized and programs on social skills training are arranged, but the problem still exists. More resources or innovative proposals may be required in this area.

In this study, relatives' social network gives them instrumental support in coping with the illness and enables them to have their own social entertainment. Though most relatives are new immigrants, they maintain some old contacts and have no problem in establishing new ones because of the large number of Chinese immigrants in Toronto. Very few of them have attended the relative support groups. One parent mentioned that winter was a problem for her and another one had to rely on available rides. This implies that mutual help support group approach for aged parents may not be very effective without further supportive arrangements.

Families in this study report double barriers in their coping. These are social stigma and the vulnerabilities of being a new immigrant. The strong stigma attached to mental illness makes the acceptance of the illness difficult for most families. The negative public attitude towards mental illness increases relatives' feeling of shame and fear of discrimination in housing, social relationships and marriage. The internalization of social stigma creates anxiety for relatives about their members and perpetuates the struggles against the "patient" identity for persons with the illness.

Social stigma affects how persons with mental illness perceive themselves. In this study, some accept their illness as their core identity while the others struggle to establish their personhood apart from the illness. For the former group, most tend to take up the dependent patient status. For the latter group, they vary from denying the illness to working hard to establish a positive self and to counteract the social stigma. The differences in responses between these two groups lie in whether they have a stronger sense of control or perform a more productive role.

Much of the literature has suggested that the mental health system and professionals contribute to stigmatizing mentally ill persons and developing their dependent patient identity (Gottlieb & Coppard, 1987; Leete, 1992; Lefley, 1992; Mosher, 1986; Smith, 1990). They are incapable of recognizing the capacities of persons with mental illness, and expect them to have a low level of functioning, and a poor prognosis as well as limited capacity for active participation in their lives. Professionals are also criticized for stigmatizing relatives' behaviours as a contributing factor in the patients' illness. Some literature (Cromwell & Snyder, 1993; Lord et al., 1987) states that medication may play a role in developing patient identity. Anti-psychotics constrict the alertness of patients while controlling their symptoms. No matter what are the sources of stigma, the study of Link, Cullen, Mirotznik, and Struening (1992) reported that 'labeling' activated beliefs which lead to negative consequences such as demoralization, a strained social network and unemployment. Therefore, it is important to erase the social stigma attached to mental illness and to help people with the disorder to deal with it.

Both parents and their members in this study are first generation immigrants to Canada, and the vulnerabilities of being a new immigrant hinder their coping with the illness. Lack of knowledge of community resources and how they operate creates stress for relatives in seeking for external help. Language is a major problem for access to services. Some relatives feel frustrated that their poor English skills limit their ability to solve problems for their members with the illness, and a few work hard to learn English to increase their independence. Due to their limited English ability, most persons with the illness have minimal choices in attending programs. A few had problem communicating with their English speaking psychiatrists or were admitted into a hospital outside their neighbourhood in order to have a Chinese psychiatrist. Unfamiliarity with the city requires relatives to learn to travel around so as to take their members with the illness to various services.

The barriers faced by immigrants in this study are similar to those mentioned in the literature (Baker, 1993; Stevens, 1993). However, the persistence and seriousness of schizophrenia in families makes the barriers even more profoundly felt.

The double barriers encountered by persons with schizophrenia further increase their sense of powerlessness. This study shows that persons with schizophrenia try their best to do what they believe they can to cope with the illness. Yet, some of them have a subtle feeling of powerlessness at different stages. They are overwhelmed by the onset of the symptoms, helpless with persistent symptoms, intimidated by hospital staff, uncertain about their prognosis, or reliant on their relatives. Negative social attitudes towards mental health problems and their poor English skills limit their opportunities and choices in lives. Hatfield & Lefley (1993) suggested professionals recognize the strength of persons with the illness in managing their problems so as to enable them to have more self-control. Recognition from professionals alone is insufficient to determine how much a sense of control a person has. This arises primarily out of the social, structural, cultural conditions and expectations.

Coping with mental illness entails adaptation to social constraints imposed on the persons with the illness. Warner (1994) viewed that the subsistence economy of the third world more flexibly allowed persons with psychosis to return to a productive role that matches with their level of functioning. He attributed the better outcome of patients in the developing world (found by the World Health Organization's international follow-up study of schizophrenia) to this. In his opinion, efforts to rehabilitate and reintegrate persons with persistent mental illness are only seen at times of extreme shortage of labor. Most persons with illness in this study would like to have a job that they could manage, and they are aware that it is hard for them to get a job at the present economy of Canada with their less competitive work capacities. They require assistance to learn how to deal with this social constraint without a feeling of powerlessness. At the same time, the society needs to take more responsibility to include them into the labor force.

8.1.4 Cultural Influences

In Chinese culture, collectivism is highly valued; an important aspect of collectivism is the perception that family is a basic social unit (Bond & Hwang, 1992). Lin & Lin (1981) and Gaw (cited in Lefley, 1985) stressed the importance of including relatives when working with Chinese psychiatric patients. This study finds that there is a high degree of involvement by relatives in coping with schizophrenia among Chinese families, and suggests that the first generation Chinese immigrants still uphold the value of family obligation in taking care of their members in need.

Relatives in this study are found to be involved in the way that they perceive their roles. This is in stark contrast with Hanson's study (1993) on white families, wherein relatives became involved in response to support from mental health professionals. The relatives did not have much of a role to play when their members were hospitalized, and they had to care for their members and to obtain resources for them when they were discharged. If the treatment of their members was stable, relatives' roles varied between the hospital and community programs as directed by mental health professionals. If their members withdrew from all formal help, relatives felt forced to re-assume the total care-giving role. Comparing my study and Hanson's study, it appears that Chinese relatives choose to become involved in their members' coping and white relatives assumed their role as demanded by the supportive situation of their members. Reports from relatives, members of the National Alliance for the Mentally ill in U.S.A. (Lefley, 1987a) indicated that the care-giving role was accepted not in lieu of, but due to a lack of acceptable community alternatives. Lefley (1987a) suggested to include cultural norms in viewing relatives' care-giving role. The difference of these two studies may due to the cultural collectivism of Chinese which regards family as a basic social unit to care for their members' needs, and the individuality in western culture, which expects societal support to assist an adult to be independent.

The attitude of a cultural group towards care-giving may affect their burden and responses to mental illness. The study of Horwitz & Reinhard (1995) showed that black parents reported less stress than white parents with equivalent amount of care-giving to adult children with mental illness as the care-giving role was perceived as more normative in the black culture. In turn, parents' level of burden influences their ill members. Persons with mental illness seem to do better in cultures where family care-giving is viewed as a valued involvement rather than a burdensome activity (Horwitz & Reinhard, 1995).

In addition to the cultural perception of the care-giving role, family structure also affects the burden experienced by relatives. Warner (1994) noticed that the extended family structure commonly found in the third World allows a diffusion of emotional over-involvement and interdependence among family members. This contributes to a better outcome for persons with schizophrenia. With more resources in the family, individual relatives can be less stressed and have lower levels of expressed emotion. Parents in this study appeared to be very patient and tolerant, and are aware of the need for creating a stress–free environment for their members to live in. Assistance from other adult children is one of the supports that helps to diffuse their burden.

Traditionally, Chinese stress the concept of family and do not have a well developed construct of individuality. Sue (1994) commented that the Chinese stress collectivist rather than individualistic identity. They are more apt to see family needs rather than individual needs. This may be the reason why parents are less sensitive to the independence needs of their members with the illness, and the sick member is less able to express their individual needs. Moreover, Chinese are not socialized to express their feelings and they have difficulties sharing how they feel with other members. This lack of effective communication between parents and members with illness becomes a problem in the dependent and conflict type of interaction.

Chinese hold a multifaceted view of the etiology of mental illness, and most families in this study attribute the cause of mental illness to external factors such as fate, immigration problems and social pressures. This perception helps them to achieve greater acceptance of the illness. There is a folk belief among the Chinese that persons with mental illness cannot take much stimulation, and this in some way encourages relative involvement in providing a stress free environment for their members with the illness.

Chinese stress collectivism and play down concerns with the self. Family is regarded as the basic social unit and functions to care for its members. The sense of family obligation is cultivated from early childhood. This perception of the family's role is well reflected in the present study. The parents as the main care-giver and other siblings as extended support network help the members with schizophrenia to cope with the illness.

8.1.5 Research Process In Two Languages

Language captures cultural uniqueness, and reflects the reality construct of its speakers. In studies of particular ethnic communities, it is advantageous to have persons who speak the ethnic language and understand their culture doing the primary research. This not only facilitates the flow of the interviews and encourages participants to confide more, but also enhances the accuracy in understanding and interpreting the data. However, it is difficult to have a direct translation of the collected information into another language. In this study, I faced a dynamic in translation at the time of report writing. On the one hand, I had to translate the voices of the participants to make them understandable by English speaking readers. On the other hand, I wished to keep intact the reality constructed by the participants and wished to describe their discourse as closely as possible.

8.2 Limitation

The limitation of this study is that participants are families in which both relatives and their members with schizophrenia agree to be interviewed as well as clients of an ethnic specific agency, this implies that they are in some kind of workable relationship with resources. Therefore, families with fewer resources in which the members with the illness are rejected are not covered in this study. It is recommended to have further research to study this type of family to find out the reasons for rejection, in order to develop preventive measures.

8.3 Implications

The stress-vulnerability-protective model (Glynn & Liberman, 1990) provides a useful framework to explore how persons with serious and persistent mental illness relate with their relatives in managing the illness. For this embraces the experiences of both parties in the coping process with the foci of protective factors and stressors. Family literature stresses families' burden and their adaptation to the illness without active involvement of their sick members, since they are perceived as passive recipients of their care. However, consumers see that they themselves have an active role in dealing with their illness. They would like to take charge of their lives, and thus run into significant conflict with their relatives over the issue of control. The dual perspective adopted in this study is an important conceptual shift from polarizing family or consumer perspective into one which incorporates both views to work towards the common goal of reducing the impact of the illness on the afflicted person and thus the family as a whole.

With this dual perspective, the present study is able to reveal the different types of relationships between persons with schizophrenia and their relatives. The findings imply a need for social work interventions on familial relationships, which aim to enable relatives and their ill members to develop a constructive relationship and thus maximize the coping potentials in families. The interventions should enable parents to recognize the capacities and independence needs of their ill members, and to adjust their degree of involvement. It is not easy for parents to have a realistic appreciation of their ill members' capacities and to establish appropriate expectations of them, especially with their emotional involvement and perceptions of illness and recovery. They require professional assistance to work towards better communications with their members with the illness. Persons with the illness also demand professional support to express their independence needs and to try out their potential in a safe familial context, in which relatives allow their members to try and to fail in their new attempts. This working model will help families to better cope with schizophrenia and is highly relevant to the existing reality in which families are expected to take greater responsibilities in the long term caring process.

The other implication of this study is for the provision of social services. Relatives are found to provide great support to their members with schizophrenia, and are ready to do so because of their strong sense of family obligation. In order to facilitate their performing this supporting role, government should provide additional assistance to them. Moreover, the sense of powerlessness among persons with the illness has to be dealt with. Provision of a network of comprehensive and accessible services which cater to their different levels of functioning will be more adequate to meet their needs with choices. With this support, they can develop their potentials to the fullest extent, improve their quality of life and promote their sense of values. In times of budget cuts in the Ontario government, it is essential to examine the cost-effectiveness of services so as to better utilize limited resources.

There are double barriers for the interviewed families to cope with schizophrenia. One is the institutional barrier to services due to language problems. The barrier has been well documented and there is a recommendation for services to ensure the needs of consumers and their relatives are met in accordance with their social contexts. The government has to take this problem more seriously to fulfill its commitment to providing equal access to care.

Social stigma is another barrier that interviewed families reported. In dealing with the objective discrimination, change is required on the macro level. This includes more public education to disseminate realistic information about mental illness, increased opportunities for the public to contact persons with the illness, and initiatives to the commercial sector to hire persons with mental illness. For the subjective self-stigmatization, I recommend services that focus on empowering persons with mental illness. These services provide them with an enriched environment, allowing them to experience control and a sense of achievement, with the aim of helping them to overcome negative valuations and to gain competence.

The existing model of having community mental health centers especially serve minority groups is very helpful to reduce the double barriers in coping with the illness. This study suggests the continued need for support to these agencies.

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Appendix A

DSM IV Diagnostic Criteria for Schizophrenia

A. Characteristic symptoms: Two (or more) of the following, each present for a significant portion of time during a one-month period (or less if successfully treated):

1. Delusions
2. Hallucinations
3. Disorganized speech
4. Grossly disorganized or catatonic behaviour
5. Negative symptoms, i.e. affective flattening, alogia, or avolition

Note: Only one criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other.

B. Social/occupational dysfunction: For a significant portion of the time since the onset of the disturbance, one or major areas of functioning such as work, interpersonal relationship, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).

C. Duration: Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptom (or less if successfully treated) that meet criterion A (i.e., active phrase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. Schizoaffective and Mood Disorder exclusion: Schizoaffective disorder and Mood Disorder With Psychotic Features have been rules out because either (1) no Major Depression, Manic, or Mixed Episodes have occurred concurrently with the active-phrase symptoms; or (2) if mood episodes have occurred during active-phrase symptoms, their total duration have been brief relative to the duration of the active and residual periods.

E. Substance/general medical condition exclusion: The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

Relationship to a pervasive Developmental Disorder: If there is a history of Autistic Disorder or another pervasive Developmental Disorder, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).

Appendix B

Interview Guide:

Member with schizophrenia

1) Tell me how your illness began.

2) How does the illness change over time?

3) How do you find your illness now?

4) What do you think that cause your illness?

5) How do you see yourself of having the illness?

6) How does the illness affect you and your life?

7) How do you cope with the impact of the illness on you?

8) What do you think that your family have helped you to cope with the impact?

9) How do your family perceive your illness?

10) What is your role in your family?

11) Do your family allow you to make your own decision?

12) How does your family make decision, and who has the power?

13) How would you describe your family relationship, and who is most closed to you?

14) What kind of life that you would like to have?

15) What would you like to do if you can?

16) How do you use your time?

17) How do Chinese see mental illness?

18) What mental health services that you have used and which you find most useful?

Parent/s

1) Tell me how your son's/daughter's illness began.

2) How has his/her illness changed over time?

3) How do you find his/her illness at present?

4) How do you see his/her illness? What do you think its cause is?

5) How do the illness affect him/her? What the family have done to help him to overcome the impact?

6) What are the impact of his/her illness on the family?

7) How do you deal with these impact? What services that you have used to help you deal with the problem? Which service that you find most useful?

8) Any other things in the family that make you worry?

9) How do you find the family relationship?

10) How do your family make decision?

11) What do you expect your son/daughter?

12) What would you like to do if you can?

13) How do Chinese see mental illness?

Appendix C

Demographic Data:

Member with schizophrenia:

age, sex, marital status, educational background, duration of illness, age of onset of the illness, suicidal or aggressive behaviours, hospitalization record, living arrangement (with family, independent living, or in supportive housing program), country of origin, years in Canada, source of income/financial support

Family: composition, education, financial background, occupation, living arrangement

Appendix D

CONSENT FORM

This study, **Coping With Schizophrenia Among Chinese Families in Toronto,** aims to understand how you and your family manage and cope with schizophrenia. It is being conducted by Christina Wai Mei Chan, a graduate student in the *Master of Social Work Program* at York University to fulfill a degree requirement.

All information shared in the interview will be held strictly confidential and participation is completely voluntary. Your name and any identifying information will not be used in the final report of this study. Summary of the study will be available for you if you wish.

The study procedure will include one to two interviews with you and one of your family members. Each interview should take from one to two hours, and will be tape recorded and transcribed by the interviewer. All tapes will be erased following the completion of the study. You will be able to review the transcript of your interview. You may decline to answer any question and you may discontinue the interview or withdraw from the study at any point in the process.

There are no apparent risks to this study. However, you may find it tiring to participate in a two hour interview. While you may not directly benefit from this study, sharing your coping experiences may lead to the development of improved social work interventions.

Any concerns or comments you may have about the study and your participation in it may be addressed to the interviewer at (416) 493-2214 or the supervisor, Atsuko Matsuoka at (416) 736-2100 Ext. 66328.

I have been provided information about the study to my satisfaction, and have agreed to have an interviewer record my responses. I understand that I am not obligated to participate in this study and that I may withdraw from the study at any time.

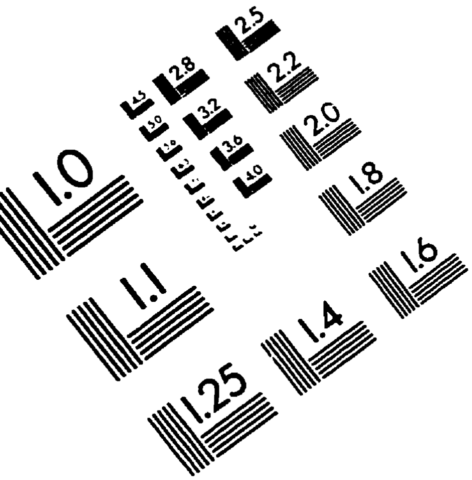
I acknowledge that I have received a copy of this consent form and I consent to take part in this study.

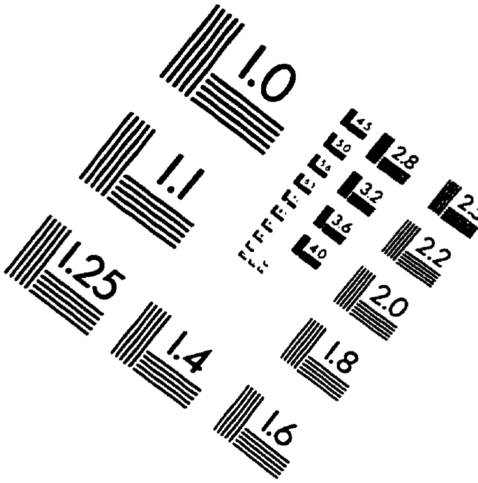
(Signature of interviewer)

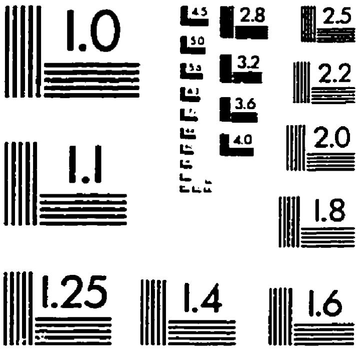
(signature of participant)

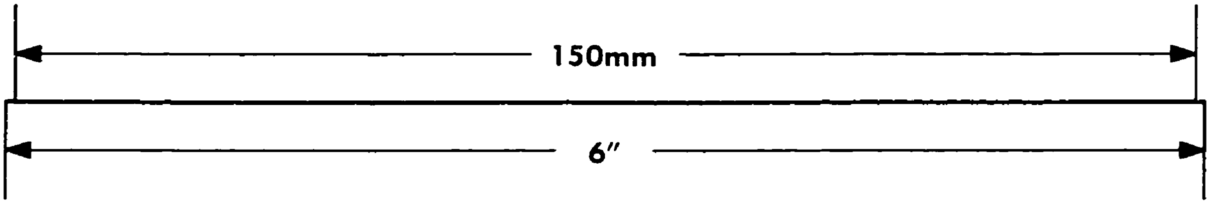
(Date)

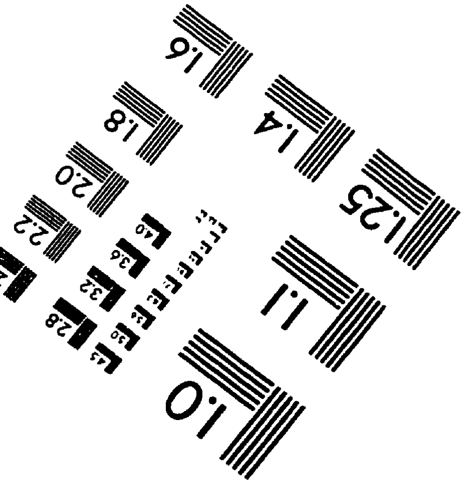
IMAGE EVALUATION
TEST TARGET (QA-3)











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