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ASSESSING REHABILITATION NEEDS OF CAREGIVERS OF PEOPLE WITH SCHIZOPHRENIA IN HONG KONG

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M.Phil

The Hong Kong Polytechnic University

2013

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Assessing Rehabilitation Needs of Caregivers of People with Schizophrenia in Hong Kong

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A thesis submitted in partial fulfillment of the
requirements for the degree of Master of
Philosophy

March 2012

CERTIFICATE OF ORIGINALITY

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ABSTRACT

Objective: Schizophrenia is a chronic and disabling mental illness that does not only affect clients but also their family caregivers. The study validated the PRNQ-C for assessing perceived needs of caregivers of people with schizophrenia, investigated the perceived needs of caregivers, and formulated recommendations to policy development and clinical practice. Method: A validation study was conducted to examine the psychometric properties of PRNQ-C before it was employed as the assessment tool to explore the perceived needs among 98 caregivers. Results: The instrument was found to have robust factor structure, statistically acceptable internal consistency, and test-retest reliability. Knowledge on mental illness, stress management, and societal and financial support were perceived to be important rehabilitation needs by the caregivers. Family intervention and emergency services were found to be the most needed rehabilitation services. Perceived needs were closely related to some demographic variables such as living condition and employment status. Finally, correlation between perceived importance and satisfaction of needs was found in some items. Conclusions: The PRNQ-C is a psychometrically sound instrument for use in Hong Kong to assess perceived rehabilitation needs of caregivers of people with schizophrenia. The findings have important implications to public policy, clinical practice, and further research.

PUBLICATIONS ARISING FROM THE THESIS

1. Wong, A.H.H., Tsang, H.W.H., **Li, S.M.Y**., Fung, K.M.T., Chung, R.C.K. & Leung, A.Y., et al. (2011). Development and Validation of Perceived Rehabilitation Needs Questionnaire for People with Schizophrenia (PRNQ-S). Quality of Life Research, 20, 447-456.
2. Tsang, H.W.H., Li, D., Tsui, M.C.M., Chung R.C.K., Wong, A.H.H., **Li, S.M.Y**., Fung, K.M.T. & Yiu, M.G.C. (in press). The Perceived Rehabilitation Needs of People with Schizophrenia in Hong Kong: Perspectives from Consumers and Care-givers, Administrative and Policy in Mental Health and Mental Health Services Research.
3. Li, D., **Li, S.M.Y**., Tsang, H.W.H., Wong, A.H.H., Fung, K.M.T., Chung, R.C.K., Yiu, M.G.C., Tam, K.L. & Lee, T.H. (under 2nd review). Development and Validation of Perceived Rehabilitation Needs Questionnaire for Caregivers of People with Schizophrenia (PRNQ-C). Rehabilitation Psychology.

ACKNOWLEDGEMENTS

Throughout the journey of my MPhil study, it has been a fruitful and valuable process. I would like to express my immense gratitude to my supervisor, Prof. Hector Tsang, for his precious guidance, encouragement, critique and feedback in helping my academic and personal growth. I am really grateful to work with his enthusiastic research team. The completion of this MPhil study would not have succeeded without his invaluable advice.

I would like to thank Yung Fung Shee Psychiatric Centre, Richmond Fellowship of Hong Kong and The Hong Kong Family Link Mental Health Advocacy Association for their great effort and support in case recruitment in our study.

Completing my MPhil study required a team of supportive members. I was grateful to my teammates including Kelvin, Alvin, Raymond, Ada, Christopher, June, Doris, Edward who provided me valuable opinions and support throughout this study. Moreover, I need to give my heartfelt thanks to Kenny and my family members for their psychological support in helping me overcome my difficult times.

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CHAPTER 1. INTRODUCTION

1.1 OVERVIEW OF STUDY

Schizophrenia is a chronic and distressing mental illness constituting one of the ten leading causes of the disability in the world (Murray & Lopez, 1996). Their recovery is heavily undermined by the disruptive symptoms and their inadequate skills (Fung et al., 2007; Tsang & Chen, 2007). Schizophrenia does not only affect consumers but also their family members and primary caregivers. The caregivers serve a critical role in the daily care of the patients (Yeh et al., 2008). Unfortunately, the caregivers face a range of challenges which points to the need for rehabilitation services to relieve their burden. Investigating the needs of caregivers of people with schizophrenia could be of help for formulation of services and public policy. However, local research on the needs of caregivers of mental health consumers is limited. This study aimed at gaining scientific evidence which could provide better understanding on the needs of caregivers of people with schizophrenia which could fill the data gap in Hong Kong and help psychiatric rehabilitation policy formation and development in future.

1.2 PURPOSE OF STUDY

1 To initially investigate the psychometric properties of a questionnaire for assessing perceived needs of caregivers of people with schizophrenia

2 To investigate perceived needs of caregivers of people with schizophrenia via a quantitative survey using the questionnaire validated in phase one

3 To inform policy makers for the formulation of public policy related to psychiatric rehabilitation

1.3 SIGNIFICANCE OF STUDY

Research addressing the needs of caregivers of people with schizophrenia in Hong Kong is limited (Tsang, Pearson & Yuen, 2002; Yip, 2004). In this study, the Perceived Rehabilitation Needs Questionnaires for Caregiver of People with Schizophrenia (PRNQ-C) we validated may serve as the standardized instrument to assess the perceived needs of caregivers of people with schizophrenia in the long run which will help the government and service providers to better understand their needs. The results of the quantitative survey can be used as a reference in reviewing the importance and adequacy of existing mental health policy and services for the caregivers in Hong Kong. Better understanding of their needs can help develop relevant policies and psychiatric services based on their needs. The government can thus better allocate and prioritize resources in determining the formulation of psychiatric services to meet their needs.

CHAPTER 2. LITERTURE REVIEW

2.1CAREGIVERS OF PEOPLE WITH SCHIZOPHRENIA

Schizophrenia is a chronic and disabling mental disability which causes numerous challenges in its management and consequences (Awad, Voruganti & Heselgrave, 1995). Schizophrenia is a major contributor to the global burden of disease (WHO, 2001). Among different kinds of psychiatric disorder, schizophrenia constituted one of the ten leading causes of the disability in the world (Murray & Lopez, 1996). About 24 million people have schizophrenia globally as estimated by the World Health Organization (2012). Schizophrenia affects 7 per 1,000 of the adult population. Those who suffered from this condition were mostly aged between 15 to 35 years old (Chan, 2011). In Hong Kong, it is estimated that about 60 000 people are suffering from schizophrenia and other psychotic disorders which constituted 80% of hospitalized mental patients (Hospital Authority Hong Kong 2002; Chan & Yu, 2004). In China, the prevalence rate of schizophrenia was 6.6 per 1000 among individuals aged 15 or above which translated to 6.6 million of individuals (Chen, et al., 1998).

Schizophrenia does not only affect consumers but also their family members and primary caregivers. Over the past 20 years, psychiatric care has been focusing on deinstitutionalization and community based care. However, inadequate support in the community has led to a shift of care for patients from formal healthcare system to informal care providers and the family will thus bear the responsibility of patient care (Hou et al., 2008; Awad & Voruganti, 2008). Individuals with schizophrenia are liable to relapse and frequent hospitalizations (Goldacre, Shiwak & Yates, 1994; Wing, 1994). People with schizophrenia may suffer from positive symptoms such as delusion and hallucination; negative symptoms such as emotional and social withdrawal; and a range of cognitive deficits and affective symptoms such as depression and agitation (Liddle, 1987). Beyond the range of disabling symptoms, personality changes, and role and social functioning impairment are prominent component of the illness (Mueser & MuGurk, 2004). As a result, individuals with schizophrenia become a significant family concern. Similar to United States and United Kingdom, the majority of people with schizophrenia live with their family in Hong Kong and more than half of them depend on the assistance and continued involvement of their families (Chien, Chan & Morrissey, 2007; Pearson, 2008).

The caregivers play a critical role and are the major resource in the daily care of the patients (Yeh et al., 2008). The caregivers look after their family members with schizophrenia with love and devotion. Unfortunately, family member receive little recognition for their valuable work and no financial support (Chan, 2011). Many of them may experience heavy load resulting from the responsibility and lack of personal, financial and emotional support (Pearson, 2008). Taking care and living with a family member with schizophrenia is very stressful. Numerous studies showed that family caregivers of people with severe mental illness experienced much stress and a high level of burden (Li, Lambert, & Lambert, 2007; Chan, 2011). The caregivers face a range of practical and emotional stress which causes them much emotional burden (Barrowclough & Tarrier, 1992; Pearson & Ning, 1997). The stress may result from the unpredictable and bizarre behaviors of their relatives with schizophrenia, experience of social isolation caused by stigmatization and upon the family, emotional frustration such as guilt and loneliness, and family conflicts in the caring process (Chien et al., 2007). The ineffective and inadequate mental health services such as a lack of social and vocational intervention for patients, the unemployment of the patients and reluctance to attend medical follow up or take medication, frustration, and anxiety during the process of rehabilitation further make the caregiver feel stressful (Tsang et al., 2003).

The role of caregivers had become increasingly important in patient care in the community. Burden on the family refers to the consequences for those in close contact with a person with severe mental illness (Chan, 2011). Caregiver burden was defined as “a psychological state that ensues from the combination of the physical work, emotional and social pressure, like the economic restriction that arise of taking of taking care of the patients” (Dillehay & Sandys, 1990). The key caregiver refers to the person who provides most of the support and devotes substantial time in taking care of the patient (Gutierrez-Maldonado, Caqueo-Urizar & Kavanagh, 2005). Some researchers further divide burden into objective and subjective (Schene, 1990). Caregivers of people with schizophrenia are often overwhelmed by both subjective and objective burden (Ivarsson, Sidenvall & Carlsson, 2004; Li et al., 2007; Tsang et al., 2002). Subjective burden is regarded as the emotional distress and other psychiatric reaction resulting from the provision of care to the family member with mental illness experienced by caregivers. Objective burden refers to the concrete and observable costs on family's physical and psychological well-being due to the symptoms, behavior and socio-demographic characteristics (Hoenig & Hamilton, 1966). Subjective burden among caregivers of people with severe mental illness in US pertains to the symptomatic behaviors of the care recipients, while the objective burden is associated with the caregiving demands that restrict their participation in personal activities (Baronet, 1999). In Europe, either subjective or objective burden is closely linked to caregivers' worries about the health conditions, future, safety, and financial support to the care recipients (Thornicroft et al., 2004). Consistent with these findings, Tsang et al. (2002) has suggested a four-factor model regarding the caregivers' burden of people with severe mental illness. These include the burden brought by the symptom-specific behaviors of care recipients, and the social, emotional, and financial burden experienced by caregivers. The burden causes extensive impact on the lives of the caregivers, such as financial difficulty, limited social activities, feeling of low self-esteem and helplessness, family conflicts, and not having enough time to take care of other family members and domestic routines (Chan, 1996; Wong, 2006; Wong et al., 2004). The burden of caring of people with schizophrenia is associated with reduced quality of life and significant impacts on the health and functioning of caregivers (Caqueo-Urizar & Gutierrez-Maldonado, 2006). All of the above point to the needs for rehabilitation and supporting services to relieve their burdens. The multi-faceted needs of caregivers include emotional support, self-management, financial security, engagement in employment opportunities, collaboration with professionals, and rehabilitative services provided to the care recipients (Tsang et al., 2002).

2.2 NEEDS

Human behavior and social interaction can be explained by the drive of human needs (Yen, 2008). A list of human needs to account for behavior and motivation was defined by Murray (1938) which included needs connected to inanimate objects, expression of ambition, power, injury to self or others, affection, and other social goals. This definition attempted to classify the full range of human needs which have been proved to have high authority. Maslow (1954) listed five different levels of needs according to psychological development of human, which are physiological, safety, love, esteem and self actualization needs regarding the psychological development of people. The definition of needs by Murray and Maslow has been regarded as the fundamental and theoretical one. However, it is seldom applied to the field of psychiatric rehabilitation in understanding needs of people with mental illness and their caregivers.

In mental health services, need is defined as the requirements of individuals to enable them to achieve, maintain, or restore an acceptable level of social independence or quality of life (Department of Health Social Services Inspectorate, 1991). Need may be measured in both subjective and objective manner through the normative, perceived, expressed, and relative perspectives (Bradshaw, 1972). Normative needs is "the existence of some standards or criterion established by custom, authority, or general consensus against which the quantity or quality of a situation or conditions is measured", and perceived needs can be regarded as "what people think their need are or feel their needs to be". Expressed need is regarded as "the actual attempts to obtain a service rather than judges by some experts that the individual needs that service", and the relative need is regarded as "the gap between the level of service existing in one community and those existing in similar communities or geographic areas".

Van Haaster et al. (1994b) defined needs into three levels: the problems experienced by the client (patients or relatives); the interventions required to alleviate or limit these problems; and the services required to provide these intervention. Therefore, it is suggested that needs should be assessed at the intervention level and not at the problem level.

Caregivers of people with mental illness have substantial needs (Hoenig & Hamilton, 1996). Steven and Gabbay (1991) define need as what people can benefit from but not what people ask for. It was suggested by Phelan et al (1995) that a good scale for need assessment should take the perspectives of both caregiver and service provider into account to assess the comprehensive needs of caregivers. In order to meet caregivers needs, Najim & McCorne (2005) suggested that there must be negotiation between service users and service providers. To understand caregivers' needs, an individualized and goal-oriented service would be considered by service provider in order to fulfill their needs (Conning & Rowland, 1992).

2.3NEEDS ASSESSEMENTS

Eklund and Backstrom (2005) suggested that satisfaction with medical care serves as the mediator for better quality of life. The concept of need can motivate medical service providers to provide particular service to meet the need of service consumers (Slade, Thornicroft & Loftus, 1999). A review of clients' needs will contribute to the formulation of culturally relevant psychiatric services and help policy makers set priorities on mental health services towards caregivers of people with schizophrenia (Koppel & McGuffin, 1999). Valid need assessment instruments are of uppermost importance to help us identify the healthcare needs and unmet needs of clients (Van den Bos & Triemstra, 1999). The assessment should cover a spectrum of need aspects, such as health care, social welfare, housing, employment, etc. In previous studies, both qualitative and quantitative approaches were used to assess the needs of caregivers in order to provide accurate and comprehensive information for policy making.

Focus group is the most commonly used strategy among the qualitative approaches to explore views of service users (Green & Thorogood, 2004). Wagner and King (2005) conducted a qualitative study involving focus groups of people with mental illness and caregivers to examine their perceptions of the existential needs of people with psychotic disorders. Wancata and colleagues (2006) conducted a study using focus groups and interviews to identify problems of schizophrenia caregivers and which interventions are required for each of these problem. Wong et al. (2011) conducted a study using focus group interviews to identify the perceived rehabilitation needs of people with schizophrenia. According to the above studies, focus group was a useful technique to collect information from different service users in the psychosocial field.

Towards the quantitative approach, standardized need assessment is the tool to gain more understanding of the health related quality of life via the process of identifying their healthcare needs and the unmet healthcare demands (Van de Bos & Triemstra, 1999). Camberwell Assessment of Need (CAN) developed by the Psychiatric Research in Service Measurement (PRiSM) at the Institute of Psychiatry in London (Cleary et al., 2006; Slade et al., 1999) is the most commonly used need assessment to measure the health and social needs of people with mental disorder. CAN is carried out as a structured interview in which staff, consumer and caregiver views of need are assessed separately. It is a 3-points scale with 22 items in which divided into three major factors: functional disability, social loneliness and emotional loneliness. However, the psychometric properties of CAN are weak in having low internal consistency and uncertain convergent validity (McCrone et al., 2000; Slade et al, 1999). Also CAN adopted a narrow perspective which lacks the perspective of users (Wanger & King, 2005). A good needs assessment should take the users' view into account.

Another need assessment that is widely accepted and developed for adults with mental health problem is the Medical Research Council Needs for Care Assessment

(MRC-NCA; Mangen & Brewin, 1991). It is an assessment of functioning that includes psychiatric symptoms and social role performance (Grosser & Flisher, 1997). This assessment focuses on service outcome rather than on individual needs and not appropriate to measure caregivers' needs (Yen, 2008). The Avon Mental Health Measure (AMHM; Avon Measure Working Group, 1996) is conducted as self-report by service user and major caregivers. This is the most user-centered instrument. But no information is available on its validity and reliability (Evan, Greenhalgh & Connelly, 2000). Another instrument that assesses caregivers' needs is the Relatives' Cardinal Needs Schedule (RCNS; Barrowclough et al., 1998). However, Wancata et al. (2006) commented that the views of the caregivers are restricted to their willingness to accept the help of the given problem. In addition, the needs of caregivers are assessed at the problem level, but not at the intervention level. RCNS did not provide a comprehensive assessment of all needs of the carers, and some problem areas are excluded. The items of RCNS were relied exclusively on review paper, but not on in-depth interview with caregivers or expert (Wancata et al., 2006).

A previous study conducted in Taiwan identified four major clusters of needs among those caregivers using the Family Caregiver Burden and Need Schedule (Yeh et al., 2008). In addition, two studies conducted in mainland China using the translated Chinese Caregiver Burden Scale and Scale of Needs (SON) were used to assess the extent of caregivers' burden and dimensions of needs (Li et al., 2007; Yen, 2008). However, all of these instruments failed to identify the multi-faceted needs in regards of the societal, welfare, and medical support among caregivers of people with schizophrenia together with the clients' satisfaction with the existing services. The above review demonstrated that the majority of studies adopted a narrow perspective in understanding the needs of caregivers of people with schizophrenia.

2.4 LOCAL STUDIES AND TOOLS ON NEED ASSESSMENT

In Hong Kong, similar studies to assess the needs of caregivers of people with schizophrenia are extremely limited. Studies in this area were conducted in many other countries such as Australia, Europe and Taiwan (Meadows et al. 2000, Korkeila et al. 2005, Yeh et al. 2006). All of these studies used the needs assessment tools to investigate the perceived needs of caregivers of people with mental illness. Literature review suggests that there is a lack of local and comprehensively validated assessment instruments which may be used to assess the needs of the caregivers of people with schizophrenia in Chinese population. Translation of previously developed instruments may only be the choice when assessing those people whose language is not English. However, most of the mentioned instruments only focus on clinical aspects of needs which are clinically oriented. The CAN scale is one of the most commonly used need assessment tools. However, it is not culturally relevant for use in Chinese communities. Assessment instruments that are tailor-made for the purpose of public policy development are limited. Family Caregiver Burden and Need Schedule (Yeh et al., 2008) and Chinese version Scale of Needs (Yen, 2008) had been used to assess the burden and needs of caregiver of people with schizophrenia in Chinese population. Moreover, all of these instruments did not assess the needs in a comprehensive manner together with their satisfaction with the exiting services. In order to formulate a comprehensive mental health policy to fulfill the needs of caregivers of people with schizophrenia in Hong Kong and Chinese population, there is an urgent need to develop and validate a culturally relevant and multi-faceted need instrument to better understand their needs. This study is to develop instruments that systematically collect opinions from caregivers about their perceived importance on various aspects of their needs. With the result, the government can develop services from a client-centered approach.

Table 1. The strength and weakness of existing instruments

Need assessment	Strength	Weakness
CAN	- One of the most widely accepted need assessment instruments	- Psychometric properties are weak. - Adopted a narrow perspective which lacks the perspective of users
MRC-NCA	- Another widely accepted need assessment instrument for adults with psychiatric disorder	- Focuses only on service outcome rather than on individual needs and not appropriate to measure caregivers' needs
AMHM	- This is the most	- No formal data on the psychometric

	user-centered instrument as it is conducted as self-report	properties of the AMHA are available
RCNS	- This has been developed specifically to measure the need for psychosocial intervention in families	- The views of the caregivers are restricted to their willingness to accept the help of the given problem - Did not provide a comprehensive assessment of all needs of the carers, and some problem areas are excluded - The items of RCNS were relied exclusively on review paper, but not on in-depth interview with caregivers or expert
FBNS	- Identified four major clusters of needs among those caregivers which included assistance with patient care, access to relevant information, societal support and burden release	- Failed to identify the multi-faceted needs in regards of the societal, welfare, and medical support among caregivers of people with schizophrenia together with the clients' satisfaction with the existing services
SON	- It was specifically developed for caregivers of mentally ill patients in Taiwan.	- It was developed based on Taiwanese culture - Did not assess the needs in a comprehensive manner together with their satisfaction with the exiting services

2.5 SOCIAL POLICY IMPLICATION OF THIS STUDY

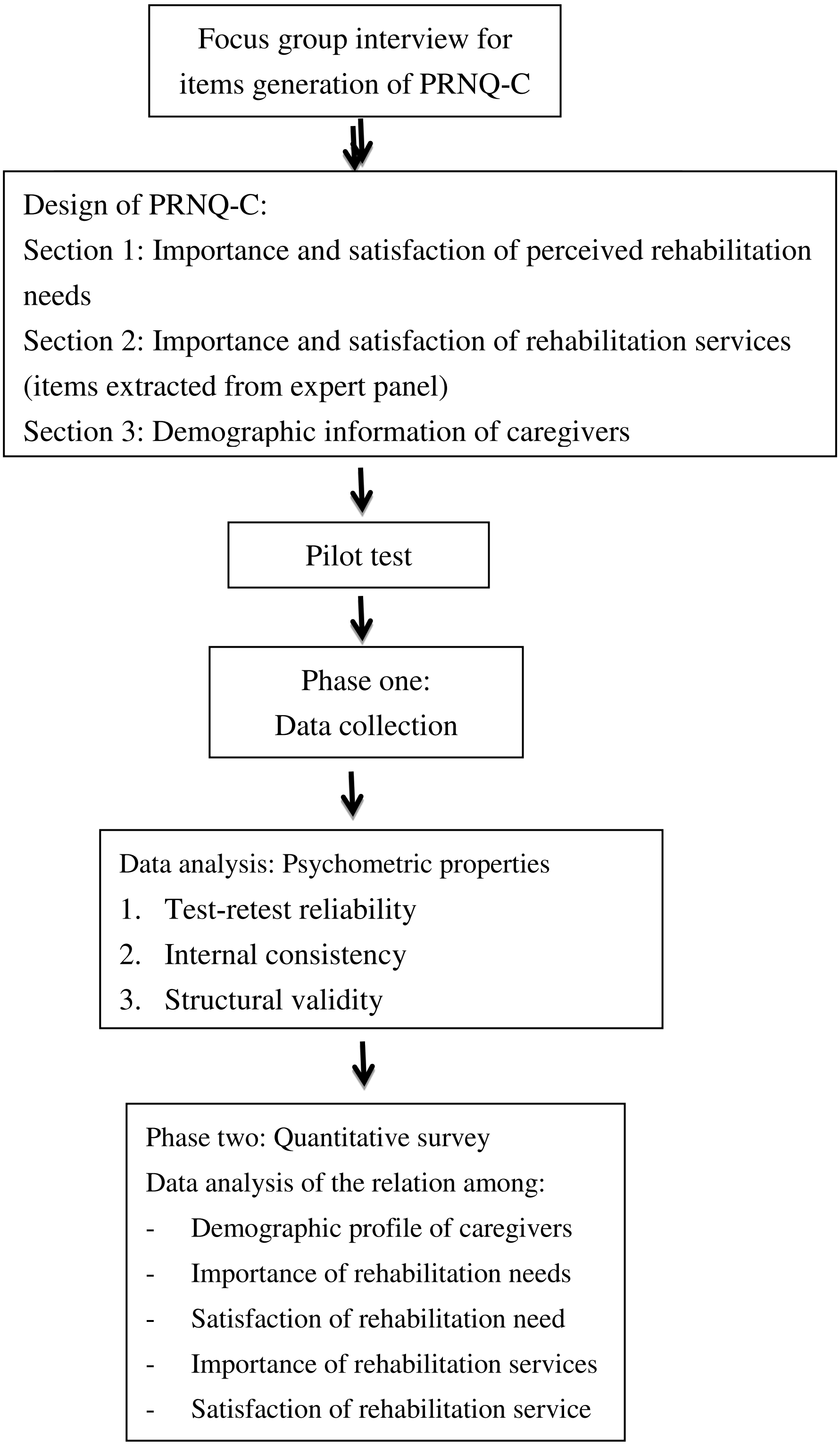
The formulation and implementation of public services is to meet those in need (Percy-Smith, 1996). As caregivers play a critical role in providing daily care and assisting the recovery of the people with schizophrenia, their burden may bring about affective responses which may indirectly block the recovery of those with schizophrenia and thus leading to relapse or readmission (Yeh et al., 2008; Chan, 2011). From a public health perspective, unresolved burdens among caregivers would have profound impact on health, sustainability of caregivers' roles, and lifelong caring relationships with care recipients with mental illness (Talley & Crews, 2007). In view of these, increasing attention has been given to the importance of providing support for caregivers in order to reduce their burden. A 'needs-led' approach is suggested by social policy researchers that the supply of services is based on a thorough analysis of perceived needs from multiple perspectives of the population (Cleary et al., 2006; Harvey & Fielding, 2003). Before resources are allocated to the community, the deficits of services and rehabilitation needs of clients and caregivers have to be well understood (Ng & Leung, 2002).The importance of assessing need for services has been fully recognized by the government in western countries (House of Commons, 1990). The Hong Kong Government published two policy papers for people with disabilities for the past decade which included the White Paper on Rehabilitation (Hong Kong Government, 1995) and the Hong Kong Rehabilitation Program Plan 1998-99 to 2002-03: Towards a New Rehabilitation Era (Health and Welfare Bureau, 1999). However, it is far from adequate as the input came only from a minority of the service users. The contents of these policy documents did not address the special needs of people with schizophrenia and their caregivers based on independent scientific study (Tsang et al., 2002; Yip, 2004). In fact, a review of clients' needs may contribute to the conceptualization of a unique psychiatric service modality and promote relevant agenda. This is an essential determinant and information in setting priorities of mental health services (Koppel & McGuffin, 1999).

Local research on rehabilitation needs of the caregivers of mental health consumers is limited which may cause the lack of a sensitive and effective policy framework for psychiatric rehabilitation in Hong Kong. Literature review suggests that there is a lack of locally validated assessment instruments which may be used to assess the needs of the caregivers of people with schizophrenia in Chinese population. Assessment instruments that are tailor-made for the purpose of public policy development are scarce. In order to better prioritize the resources and formulate future psychiatric rehabilitation policy, there is an urgent need to develop a need assessment which is culturally relevant and can provide directions for policy development in Chinese communities. By investigating the needs from various perspectives, a holistic picture will then be obtained which may help us to review the adequacy of current mental health rehabilitation services and policies and make appropriate suggestions to the Government of the HKSAR for future development.

CHAPTER 3. OVERALL DESIGN OF RESEARCH STUDY

This research study consisted of two phases. Phase one aimed to initially investigate the psychometric properties of “Perceived Rehabilitation Needs Questionnaire for Caregivers of people with Schizophrenia” (PRNQ-C) in order to ensure its psychometric properties which included test-retest reliability, internal consistency, and structural validity. Phase two applied the validated PRNQ-C to investigate the perceived rehabilitation needs of caregivers of people with schizophrenia in relation to their demographic profile and their perceived service needs via a quantitative survey using the PRNQ-C validated in phase one. Figure 1 depicts the overall design of this study.

Figure 1. Overall Design of the Study



CHAPTER 4. PHASE ONE: DEVELOPMENT AND VALIDATION OF PRNQ-C

4.1 OBJECTIVE

1) To validate a questionnaire for assessing perceived needs of caregivers of people with schizophrenia

4.2 DEVELOPMENT OF PRNQ-C

A Perceived Rehabilitation Need of Caregivers of People with Schizophrenia (PRNQ-C) was developed earlier by Tsang et al. (under review) with funds from the Research Grants Council which aimed at assessing the perceived needs of the caregivers. The development of PRNQ-C which included focus group interview, generation of preliminary codebook, calculation of concordance rates, frequency count of items, and design of the PRNQ-C were done my chief supervisor. The previous work was regarded as the foundation on which the candidate's study built and developed. The candidate investigated and gleaned data pertinent to the psychometric properties of PRNQ-C, and conducted the quantitative survey of PRNQ-C. Fourteen people with schizophrenia, thirteen caregivers of people with schizophrenia, and sixteen mental health professionals were recruited by convenience sampling from Kowloon Hospital, and three non-government organizations (NGOs) in Hong Kong including New Life Psychiatric Rehabilitation Association, the Salvation Army, and the Hong Kong Family Link Mental Health Advocacy Association for the focus group interview. The interview identified issues pertaining to the perceived needs of people with schizophrenia and their caregivers. All of them were aged from 18 to 60 and fluent in Cantonese. The patients recruited had suffered from schizophrenia for at least 1 year according to the diagnosis made by certified psychiatrists in Hong Kong following the DSM-IVcriteria (American Psychiatric Association, 1994). The caregivers of people with schizophrenia were primary caregivers and had provided care to the patients for at least 1 year. The group of mental health professionals had at least 1 year of experience working with people with schizophrenia. Table 2 shows the demographic data for the three groups in the sample.

Table2. The Demographic Information for Participants in the Focus Groups

	Focus groups		
	Schizophrenia (n=14)	Caregivers (n=13)	Professionals (n=16)
Age	39.6 ± 10.8	49.8 ± 9 .8	N/A
Sex			
Male	7 (50%)	2 (15.4%)	8(50%)
Female	7 (50%)	11 (84.6%)	8(50%)
Educational level			
Primary	3 (21.4%)	1 (7.7%)	0(0%)
Secondary	11 (78.6%)	6 (46.2%)	0(0%)
Tertiary	0 (0%)	6 (46.2%)	16 (100%)
Duration of illness	17.9 ± 11.3	N/A	N/A

Year of taking care of people with schizophrenia	N/A	7.9 ± 5.7	N/A
Experience in working in the field of mental health (Year)	N/A	N/A	6.5 ± 5

4.2.1 FOCUS GROUP INTERVIEW

Focus group interview was commonly used for exploring service users' views (Green & Thorogood, 2004) and policy research (Fontana & Frey, 1994). From May 2007 to July 2007, six focus group interviews were conducted for the development of PRNQ-C. The interviews included two for people with schizophrenia, two for caregivers of people with schizophrenia, and another two for mental health professionals. The focus group interviews followed standard procedure with trained interviewer, post-session debriefings, and audio recordings. The interview guide was developed according to the theoretical framework on family stress and caregivers' burden of people with psychiatric illness proposed by Tsang et al. (2002). Accordingly, symptom-specific, social, emotional, and financial burdens were the four key domains of burden experienced by caregivers. The focus group interview covered the following discussion points: 1) what were the difficulties that the caregivers of people with schizophrenia will face in the daily life; 2) what were their needs that may help them to solve the above difficulties and improve their quality of life as caregivers; 3) to what extent did they think that their needs were fulfilled; 4) how the existing services, resources, and government policy had addressed their needs;

and 5) what were their suggestions to the government as to how the existing services, resources, and policy for the caregivers of people with schizophrenia may be improved. The above discussion points were decided by a group of experienced mental health professionals. The interviewees were required to express their needs and opinions on the four burden domains. Each focus group lasted one and half hour with six to eight participants. Written consent was obtained from each of the participants before the focus group interview began.

4.2.2 GENERATION OF PRELIMINARY CODEBOOK

The collected data from focus group was transcribed by a research assistant for content analysis (Stemler, 2001). Based on the collected transcripts and a review of literature, a step-by-step procedure was taken to generate a codebook that identified the possible items in PRNQ-C. The generation and verification of items were separately done in different collected transcripts for the purpose of testing the validity of the generated items across different transcripts based on a sound theoretical model (Tsang et al., 2002). First, two out of six transcripts were selected to develop the codebook randomly. The items in the codebook included the problems encountered and rehabilitation needs of caregivers of people with schizophrenia. The preliminary codebook had 52 items divided into twelve categories. Forty nine items were based on the contents of transcripts and the other three items were based on literature review.

Second, two transcripts were randomly selected from the remaining four transcripts for thematic analysis by two researchers.

4.2.3 CALCULATION OF CONCORDANCE RATES

Concordance rate was calculated for its inter-coder reliability. Concordance rate was calculated by the number of agreement of the coding items of both coders divided by the total number of items. High concordance rate (96%) was found at this stage. My chief supervisor who was experienced in conducting qualitative research in psychiatric rehabilitation then supervised the two coders to discuss the inconsistent coding items until consensus was reached. The preliminary codebook was then revised with one new item added. With the revised codebook, the last two transcripts were separately coded by two researchers again to assess the inter-coder reliability. Satisfactory concordance rate (93%) was also demonstrated in the coding. My chief supervisor then supervised the two coders again to discuss the disagreement of the coding items until consensus was reached. No further amendment was made. The revised codebook was then regarded as the final version for further analysis.

4.2.4 FREQUENCY COUNT OF ITEMS

The two coders counted the frequency of the coded item with the six transcripts according to the final codebook. Sorting or grouping was made if the frequency of the item was lower than 4. Finally, 2 items were combined into 1 item based on their nature and 2 items (i.e., “avoiding high expectation of family” and “avoiding the opportunities of being discriminated”) were deleted because their meaning was not specified. Fifty items on the rehabilitation needs of caregiver of people with schizophrenia were eventually identified.

4.2.5 DESIGN OF THE PRNQ-C

Based on the finalized items of the codebook, the PRNQ-C was developed for caregivers of people with schizophrenia for measuring their perceived rehabilitation needs in different aspects. PRNQ-C includes three sections. The first section assesses their perceived importance of needs following a five-point Likert scale, with 1 denoting ‘not important’ and 5 denoting ‘very important’. This section also requires the caregiver to rate to what extent each need is satisfied by the services provided to them if they have received it before following a five-point Likert scale, with 1 denoting ‘not satisfy’ and 5 denoting ‘always satisfy’. The items in this section are based on the finalized codebook, and assessed by eight experienced mental health professionals through the application of Content Validity Ratio [CVR] (Lawshe, 1975).The mental health professionals commented that all items were valid to investigate the rehabilitation needs of the caregivers of people with schizophrenia in Hong Kong. The second section requires the participants to rate their perceived importance of different kinds of psychiatric rehabilitation services following a five-point Likert scale, with 1 denoting 'not important' and 5 denoting 'very important'. The participants also need to answer to what extent they satisfy with each kind of service if they have received it before following a five-point Likert scale, with 1 denoting 'not satisfy' and 5 denoting 'always satisfy'. The items in this section were extracted from an expert panel consisting of eight experienced mental health professionals. Thirteen rehabilitation services divided into seven categories were used in this section. There is an open-ended question about their opinion towards their rehabilitation needs or service provision at the end of the first two sections. The last section of the questionnaire is about the basic demographic information of the caregiver for further analysis.

4.3 VALIDATION OF THE PRNQ-C

After PRNQ-C was developed, a pilot test was conducted on five caregivers and assess if the questionnaire could be smoothly implemented. The next step of study was to validate PRNQ-C in terms of its test-retest reliability, internal consistency and structural validity. In this study, not all of the respondents had to fill the latter part of the first section if they had not received any service fulfilling each need. Because of the presence of a substantial number of missing data in the later part, it was considered not suitable for conducting factor analysis (Field, 2009). This study focused only on initial validation of the former part of the first section of PRNQ-C.

4.3.1 PARTICIPANTS

To obtain a stable factor structure, it was estimated that a sample size of 300 respondents was needed by taking the ‘rule-of-thumb’ of including 5-10 participants per questionnaire item (Kass & Tinsley, 1979). However, only 98 caregivers of people with schizophrenia were recruited to complete the questionnaire for the validation study. The caregivers were recruited by convenience sampling from one psychiatric center and two NGOs which provided rehabilitation and supporting services for people with mental illness and their caregivers in the community. The participants were primary caregivers who had taken care of their relatives with schizophrenia for at least 1 year. As primary caregivers, they were intimately involved in caring for the care recipients, looking after their daily needs, supervising medication, accompanying them to the hospital, and liaising with hospital staff (Nehra, Chakrabarti, Kulhara, & Sharma, 2005). The demographic characteristics of the caregivers are summarized in Table 3.

Table 3.Demographic Information of the participants (n=98) for Validation Study

Demographic variables		Frequency (Percent)
Gender	Male	38 (38.8%)
	Female	60 (61.2%)
Age	18-25	3(3.1%)
	26-35	11 (11.2%)
	36-45	14 (14.3%)
	46-55	26 (26.5%)
	56 or above	44(44.9%)
Educational level	Illiterate	6 (6.1%)

	Primary	37(37.8%)
	Secondary	48(49.0%)
	Tertiary or above	7(7.1%)
Marital status	Single	14(14.3%)
	Married	69(70.4%)
	Divorced	8(8.2%)
	Widowed	7(7.1%)
Living condition	Living with people with mental illness	76(77.6%)
	Not living with people with mental illness	22 (22.4%)
Employment status	Employed	38 (38.8%)
	Unemployed	60 (61.2%)
Year of taking care of people with schizophrenia	2 years or below	14 (14.3%)
	2-5 years	23(23.5%)
	5-10 years	18 (18.4%)
	10 years or above	43 (43.9%)

4.3.2 INSTRUMENT

Perceived Rehabilitation Need of Caregivers of People with Schizophrenia (PRNQ-C). The PRNQ-C described earlier was used for assessing perceived importance of rehabilitation needs of caregiver of people with schizophrenia (50 items) and their satisfaction towards service provision in the field of mental health (13 items). Demographic information such as age, gender, educational level, marital status, living condition, employment status and caregiving length were collected.

4.3.3 DATA COLLECTION

Written consent from each participant was obtained before data collection with clear explanation of the purpose and procedure of the study. Two trained assessors, a certified occupational therapist and a research assistant with a psychology background, conducted face to face interview for each participant. Before data collection took place, the assessors who were independent of the generation of PRNQ-C items were provided with training on the standardized administration of the instrument by supervisor. Data collection process was coordinated by the certified occupational therapist. Test-retest reliability of the instrument using the Intra-Class Correlation (ICC) coefficient was assessed by the other assessor with the same participant again with an interval of 1 to 2 weeks after the first administration. Assuming 80% statistical power of detecting difference between ICC under the null hypothesis of .60 (i.e., inadequate reliability) and under the alternative hypothesis of .80 (i.e., adequate reliability) using a two-sided F-test with a 5% significance level (Portney & Watkins, 2000), power analysis indicated that a sample of 39 caregivers had to be recruited and respond to the PRNQ-C. Thirty-two participants (82% of the estimated sample size) were finally recruited for assessing the test-retest reliability. The main reason for including fewer participants than the estimated number was because most recruited participants were employed and busy working in this study. It usually took time to wait until they were available for the interviews.

4.3.4 DATA ANALYSIS

Statistical Package for the Social Science (SPSS) version 17.0 was used in data analysis. The demographic data of the 98 caregivers and the scores of PRNQ-C were summarized by descriptive and frequency statistics. Exploratory factor analysis (EFA) was used to test the inter-correlations and the underlying factors among the 50-item PRNQ-C. The Kaiser-Mayer-Oklin (KMO) measure of sampling adequacy and the Bartlett's test of sphericity were conducted to assess the suitability of running EFA. The Kaiser-Guttman criterion (factors should have eigenvalues over one) and the scree plot were applied to identify the number of factors underlying the 50-item PRNQ-C. Items with factor loading greater than .30 were retained in the factor solution. Principal Component Analyses (PCA) comparing the results of direct oblique rotation and varimax rotation were separately performed to explore the factor structure of PRNQ-C. The solution of a direct oblique rotation was preferred if there existed significant correlations between the identified factors substantially (Schmitt, 2011). After the number of factors was determined, the internal consistency of all sub-scales was assessed by Cronbach's alpha (α).Test-retest reliability of instrument was assessed by two way mixed intraclass correlation coefficient (ICC) using scores in the first and second administrations of the scale of the 32 participants (Portney& Watkins, 1993).

4.4 RESULTS

The current sample of 98 cases did not adequately follow the 'rule-of-thumb' of including 5 to 10 participants per questionnaire item for obtaining a stable factor structure in validation study (Kass & Tinsley, 1979). The reason why only one third of the estimated and expected samples were recruited for the study was that the primary caregivers of people with schizophrenia were very busy. Not many of them could spend their time to accompany the client to attend follow up consultation at the psychiatric centre where the participants were recruited. In addition, some caregivers did not have enough time to complete the questionnaire even though they actually attended the follow up with the client. Nevertheless, the results of the Kaiser-Mayer-Oklin (KMO) measure of overall sampling adequacy (.81), the high KMO values obtained for the individual items (>.50 for all but one items), and the acceptable range of communalities (from .46 to .82, mean=.64) indicated that our sample of 98 participants provided sufficient power for performing EFA of an 50-item instrument (Field, 2009; MacCallum et al., 1999). In addition, sufficient correlations between items were demonstrated by Bartlett's test of sphericity [$\chi^2(1225)= 3642.19$, $p< .001$] for conducting EFA.

4.4.1. VALIDITY

4.4.1.1 STRUCTURAL VALIDITY

By incorporating Kaiser-Guttman criterion for retaining factors with Eigen values greater than one and the results of Cattell's scree test, an eight-factor solution was indicated to match with the factor structure of PRNQ-C. The unrotated initial solution accounted for 64.39% of the total variance regarding the rehabilitation needs of the caregivers of people with schizophrenia. In the extracted factors of PCA using the direct oblique rotation, significant correlations were demonstrated between the extracted factors in many of the occasions (Table 4). Therefore, the rotated solution using the direct oblique rotation was preferred over the varimax rotation as the independence between factors could not be assumed (Schmitt, 2011). The factor loadings of items and the internal consistencies of the identified factors are summarized in Table 5.

Table 4.Inter-Correlations between the Extracted Factors.

	Leisure	Societal	Reduced burden	Knowledge	Reduced discrimination	Work	Reduced interruption
Stress	.32**	.20*	.28**	.34**	.19	.21*	.24*
Leisure		.16	.25*	.15	.23*	.22*	.32**
Societal			.16	.27**	.03	.19	.08
Reduced burden				.24*	.15	.18	.19
Knowledge					.08	.12	.11
Reduced discrimination						.13	.12
Work							.15

* p<.05; **p<.01

Table 5.Factorial Structure and Factor Loadings of PRNQ-C items

Factor	No. of items	% of Variance	Items	Factor loading
1. Stress management (Cronbach's α=.91, ICC=.88)	8	9.76	42. Reduce the worries over the patient's future	.80
			43. Reduce the worries over the patient's safety	.74
			36. Reduce the apprehension of the change of condition of the patient	.64
			41. Obtain peer support and encouragement	.63
			39. Reduce the psychological burden due to the lack of understanding of the patient's condition	.56

			38. Reduce the worries over unexpected problem of the patient	.56
			47. Reduce the difficulty in caretaking brought by the daily habit of the patient	.50
			44. Make time to take care of the patient's daily life	.43
2. Leisure and social life (Cronbach's α=.90, ICC=.88)	7	8.18	48. Increase the time for leisure activities	.86
			50. Increase the motivation for participating in leisure activities	.80
			49. Increase the type of leisure activities	.73
			20. Expand the circle of friends in which one is the centre of the circle	.66
			21. Increase support and understanding from friends and thus expand one's social network	.51
			18. Increase time for social life	.49
			19. Reduce self isolation and social withdrawal	.43
3. Societal andfinancial support (Cronbach's α=.85, ICC=.52)	7	5.84	8. Provide support catered for the needs of caregivers	.76
			10. Provide the awareness of support	.73
			9. Provide information on identifying the kind of support required	.61
			6. Increase channels of seeking help	.57
			17. Provide sufficient money for the expense of new medication	.45
			7. Provide psychological counseling service	.42
			14. Increase support by other mental health professionals apart from doctors	.38
4. Reduced burden from supervising medication (Cronbach's α=.83, ICC=.84)	5	6.91	11. Reduce the burden of urging patient to take medication	.78
			12. Reduce the worries on the patient's taking of medication	.77
			13. Reduce the burden brought by the side effect of medication of the patient	.68
			24. Reduce the influence on the relationship between caregiver and patient resulted from urging the patient to take medication	.58
			40. Reduce the frustration brought by the fluctuation of the patient's condition	.49
5. Knowledge on illness, caring skills, and relationship (Cronbach's α=0.93, ICC=.87)	11	8.49	26. Accept some of the behaviors of the patient	.73
			27. Strengthen communication with the patient and build a mutual trust relation	.69
			25. Enhance communication skills with the patient	.68
			30. Increase caregiver's knowledge of mental illness	.66
			32. Increase channels of obtaining information	.65
			31. Be available to certified health or rehabilitation professionals (e.g., psychologist, occupational therapist, etc.) on answering enquiries	.55
			46. Understand the proper attitude of care taking	.51
			28. Provide knowledge on differentiating the	.51

			patient's personalities from the symptoms	
			45. Strengthen caring skills	.48
			22. Improve relation with other family members	.45
			23. Increase the acceptance of the patient by the family	.35
6. Reduced Discrimination (Cronbach's α=0.73, ICC=.80)	4	3.75	2. Reduce discrimination against family members of mental illness patient	.76
			33. Reduce discrimination by the society	.58
			35. Reduce the deprivation for being family member of mental illness patient	.57
			34. Reduce self-discrimination	.46
7. Work and Accommodation (Cronbach's α=.63, ICC=.75)	4	4.46	3. Able to handle one's work and take care of the patient at the same time	.79
			5. Increase living space	.56
			4. Reduce the waiting time for halfway house	.36
			37. Reduce the pressure on working and taking care of the patient at the same time	.35
8. Reduced Interruption of Life and Recognition of Caregiver's Roles (Cronbach's α=.72, ICC=.80)	4	4.90	1. Reduce the influence on one's work performance because of the phone calls made by the patient	.73
			29. Change the conception that the caregiver is responsible for the illness of the patient	.65
			15. Reduce financial reserve for the patient	.50
			16. Increase the right of managing the Comprehensive Social Security Assistance (CSSA) allowance of the patients	.45

Factor 1: Stress Management. Eight items representing the needs to relieve stress among caregivers of people with schizophrenia were retained in this factor. The factor explained 9.76% of variance of rehabilitation needs of caregivers. The internal consistency was found to be highly correlated with the items (α= .91).

Factor 2: Leisure and Social Life. Seven items belonged to this factor. This factor referred to the needs of entertainment and social life for the caregivers. The "leisure and social life" accounted for 8.18% of variance pertaining to the rehabilitation needs of the caregivers. The internal consistency (α= .90) demonstrated that the items were highly correlated.

Factor 3: Societal and Financial Support. The concerns of societal and financial support such as increasing channel of seeking help, providing psychological counseling service, and providing sufficient money for the expense of new antipsychotic medication were included in this factor. The 7-item factor accounted for 5.84% of variance of rehabilitation needs of the caregivers. The obtained internal consistency (α= .85) demonstrated high correlations between the items.

Factor 4: Reduced Burden in Supervising Medication. Five items included in this factor. The burdens and worries were related to taking antipsychotic medication, and the frustration tied with the fluctuation of patients' condition. This factor accounted for 6.91% of rehabilitation needs of the caregivers. The internal consistency (α= .83) was highly correlated with the items.

Factor 5: Knowledge on Illness, Caring Skills, and Relationship. Twelve items were included in this factor which explained 8.49% of variance of PRNQ-C. This factor was related to the knowledge on mental illness, the caring and communication skills towards people with schizophrenia, and the improvement of relationship with family members. The internal consistency of this factor (α= .93) reflected very high inter-item correlations.

Factor 6: Reduced Discrimination. Four items reflecting the needs to reduce societal and internalized stigma against family members of people with schizophrenia were included in this factor. This factor explained 3.75% of variance on the rehabilitation needs of the caregivers. Its internal consistency was found to be moderate (α= .73).

Factor 7: Work and Accommodation. This factor accounted 4.46% of the rehabilitation needs of the caregivers. Four items reflected the needs of accommodation among the people with schizophrenia, and how the caregivers were able to handle their work and take care of the patient at the same time. However, the internal consistency for this factor was relatively low (α= .63).

Factor 8: Reduced Interr*uption of Life and Recognition of Caregiver's Roles*. The four-item factor accounted for 4.90% of variance. The four items reflected the perceived needs in reducing caregiver's burden brought by the high treatment expenses and interruptions of work, and the recognition of caregivers' roles and limits. The internal consistency of this factor was moderate (α= .72).

As a result, there were a total of 8 factors generated following EFA. They were Stress Management(Number of items: N=8; Cronbach alpha: α=.91), Leisure and social life(N=7; α=0.90),Societal and financial support(N=7; α=0.85), Reduced burden from supervising mendication (N=5; α=0.84), Knowledge on illness, caring skills and relationship(N=11; α=0.93), Reduced Discrimination(N=4; α=0.73), Work and Accommodation(N=4; α=0.63) and Reduced Interruption of Life and Recognition *of Caregiver's Roles*(N=4; α=0.72).

4.4.2 RELIABILITY

4.4.2.1 INTERNAL CONSISTENCIES

Coefficient alpha of the total score of part one (perceived important of rehabilitation needs) was very good (α=0.95) and part two (satisfaction of service provision) was also very good (α=0.88). The internal consistencies of different sub-scales of part one was good which ranged from 0.63 (Work and Accommodation) to 0.93 (Knowledge on illness, caring skills and relationship), and that of part two were also very good which ranged from 0.87 to 0.89.

4.4.2.2 TEST-RETEST RELIABILITY

The ICC coefficient of the perceived importance of rehabilitation needs was .86 for the total score. The test-retest reliability was measured according to the rotated factor structure of the PRNQ-C extracted via PCA. The coefficients for its subscales ranged from .52 to .88. Except "Societal and financial support" (ICC= .52), the ICC coefficients of the subscales were found to be in the moderate to high ranges ("Stress management": ICC= .88; "Leisure and social life": ICC=. 88; "Reduced burden in supervising medication": ICC= .84; "Knowledge on illness, caring skills, and relationship": ICC=.87; "Reduced discrimination": ICC= .80; "Work and accommodation": ICC= .75; "Reduced interruption of life and recognition of caregivers' roles": ICC=.80).

4.5 DISCUSSION

4.5.1 PSYCHOMETRIC PROPERTIES OF PRNQ-C

Results of this study suggested that the PRNQ-C has excellent internal consistency. The internal consistency showed that the scale and subscales are highly reliable. The results reflected the items of the subscales measure the same construct. As to the test-retest reliability, the scale and almost all of the subscales showed good reliability. This indicated that the instrument's scores were stable over time.

An EFA was performed to explore the constructs of perceived need of caregiver of people with schizophrenia. Although it is recommended that at least a sample size of 300 is required for factor analysis to yield stable and satisfactory results (Comrey & Lee, 1992), the items if PRNQ-C could successfully be fitted in the empirically derived factor structure. The extraction of factors using a direct oblique rotation is suggested to be a more realistic approach to obtain a factor structure in EFA (Schmitt, 2011). The results showed that all of the extracted factors contained at least one item with high factor loading (>.70), which demonstrated the robustness of the factor structure (MacCallum et al., 1999). Most of the factors had satisfactory to good factor loadings and yielded an eight-factor solution which provided preliminary evidence to the content and structural validity.

Based on these results obtained, all the subscales had moderate to high internal consistencies, with a range from $\alpha = 0.63$ to $\alpha = 0.93$. Therefore the internal validity of the obtained factor structure can be assumed. According to above evidences, PRNQ-C has sounded psychometric properties for clinical and research used.

4.5.2 COMPARISON OF PRNQ-C AND OTHER ASSESSMENT TOOLS

The results of EFA showed that the factors in PRNQ-C in fact aligned well with the identified dimensions of needs among caregivers of people with mental illness in the structured “Family Caregiver Burden and Need Schedule” (Yeh et al., 2008) and the translated Chinese Scale of Needs (SON) (Yen, 2008) in the Chinese contexts. These dimensions include the caregivers’ perceived needs in familial, emotional and social support, access to relevant information on symptom management and treatment options, and release of burden brought by caregiving. On the other hand, the factor representing the caregivers’ perceived need of ‘Reduced Discrimination’ in the newly developed PRNQ-C appears to be a new dimension of perceived needs identified in a Chinese context.

A study has revealed that stigmatization constituted one of the core burdens experienced by caregivers of people with schizophrenia in a Taiwan Chinese community (Hou et al., 2008). Tsang et al. (2003) also found that much of the burden of families of individuals with mental illness was related to stigma and thus social isolation. Building on the research evidence on the negative impact of stigmatization on symptom management of psychiatric patients (Fung, Tsang, & Chan, 2010), the items concerning the needs of burden release from familial, societal, and self-discrimination (or self-stigma) were added into the developed PRNQ-C to better reflect the adverse impact of discrimination on caregivers. The extracted factor has adequately demonstrated the dimension of perceived need among caregivers regarding their perceived importance of reducing burden from discrimination and self-stigmatization.

The newly developed PRNQ-C is more diversified and comprehensive than other similar instruments available in the literature (e.g., Yeh et al., 2008; Yen, 2008). More importantly, the items in PRNQ-C contain both trans-cultural and cultural-specific dimensions of perceived rehabilitation needs among caregivers of people with schizophrenia (Caqueo-Urízar et al., 2009; Lee et al., 2006). This instrument shows potential to be applied to caregivers of people with severe mental illness in other Chinese communities such as mainland China and Taiwan for cross-cultural validation. In support of this view, some of the key domains of caregivers' needs identified in these two areas such as information needed for taking care of patients with mental illness, need of societal support, and release of caregiving burden (Yeh et al., 2008; Yen, 2008) are similar to the factor structure of PRNQ-C.

4.5.3 LIMITATION OF THE STUDY

There are some limitations in this stage of the study. First, there was insufficient sample size for the validation study. Despite high KMO values, communalities, and robust factor structure obtained, the present sample did not meet the ‘rule-of-thumb’ of including a minimum of 5 to 10 participants per questionnaire item for obtaining a stable factor structure (Kass & Tinsley, 1979). It means that the obtained factor structure in this preliminary study would require replication using larger samples in future validation studies employing exploratory and confirmatory factor analyses.

Second, the participants were recruited from a population of family caregivers in few geographical regions in Hong Kong. This could limit generalizability of the findings and cause the risk of cultural incompatibility. A further study of cross-cultural validation is therefore recommended in order to examine its cultural integrity in other Chinese communities.

Third, all of the caregivers were volunteers and the sample may not have included those with the highest level of need, which may constitute a selection bias in the result.

Fourth, some of the socio-demographic information of the caregivers had not been collected, for examples, kinship, household income and number of care hours the caregivers spent daily with the client. Further study in exploring the relation among these variables should be conducted.

4.5.4 IMPLICATION FOR RESEARCH AND POLICY DEVELOPMENT

Schizophrenia has devastating effect on the quality of life of the caregivers across cultures (Caqueo-Urízar, Gutiérrez-Maldonado, & Miranda-Castillo, 2009). The persistence in providing lifelong care and support for family members with mental illness will be seriously challenged if supporting services are not available to meet the needs of caregivers (Talley & Crews, 2007). In order to formulate appropriate policies and develop quality rehabilitation services, assessing their needs using a scientific approach is of paramount importance. The PRNQ-C was developed to directly assess the perceived importance and satisfaction of needs among caregivers of people with schizophrenia. To date, this comprehensive need assessment is the first of its kind in Hong Kong and probably in mainland China as well. It allows social policy makers to survey on the perceived needs of caregivers of people with mental illness on a regional basis. By taking a ‘needs-led’ approach of planning and health service evaluation, it allows the supply of services to be closely matched to those needed and hence provides better structuring of service delivery in the regions (Harvey & Fielding, 2003; Nielsen et al., 1999).

To conclude, the psychometric properties of the validated PRNQ-C suggest that it may be used as the research instrument for phase two if the study to explore the perceived needs of caregivers of people with schizophrenia.

CHAPTER 5. PHASE 2: A QUANTITATIVE SURVEY OF PRNQ-C

5.1 OBJECTIVES

1) To investigate the importance of perceived need and rehabilitation service of caregivers of people with schizophrenia
2) To explore the relationship between perceived need of caregivers and their socio-demographic characteristics
3) To examine the relationship between the importance and satisfaction of perceived needs among caregivers
4) To examine the relationship between the importance and satisfaction of rehabilitation service among caregivers
5) To examine the relationship between the importance of perceived needs and rehabilitation services

5.2 QUANTITATIVE SURVEY OF PRNQ-C

5.2.1 PARTICIPANTS

The sample estimation was based on the statistical software PASS 2008,(Kaysville, Utah, USA) using the concept of Cronbach's coefficient alpha for internal consistency or validation of instruments, which could be regarded as a special kind of correlational analysis. The number of items in PRNQ-C was 63 and thus a sample size of 94 subjects was needed to detect the difference between the Cronbach's coefficient alpha under the null hypothesis of 0.70 and that under the alternative hypothesis of 0.80 using a two-sided F-test with 0.05 level of significance. The final estimated sample size was round up to be 100. Following this estimation, a total of ninety-eight caregivers were recruited for this quantitative survey. They were recruited by convenience sampling from Yung Fung Shee Psychiatric Centre, and non-government organizations (NGOs) including Richmond Fellowship of Hong Kong and The Hong Kong Family Link Mental Health Advocacy Association. To be eligible for this study, the participants should be primary caregivers who had taken care of their relatives with schizophrenia for at least 1 year. As primary caregivers, they had to be intimately involved in caring for the care recipients, looking after their daily needs, supervising medication, accompanying them to the hospital, and liaising with hospital staff (Nehra et al., 2005). The demographic characteristics of the caregivers are summarized in Table 3.

5.2.2 INSTRUMENT

Perceived Rehabilitation Need of Caregivers of People with Schizophrenia (PRNQ-C). The PRNQ-C validated in phase one was used for assessing perceived importance of rehabilitation needs of caregiver of people with schizophrenia (50 items) and their satisfaction towards service provision in the field of mental health (13 items). Part one of PRNQ-C assessed the perceived importance of needs of caregivers following a five-point Likert scale, with 1 denoting ‘not important’ and 5 denoting ‘very important’. Higher score indicated higher importance of the needs or vice versa. This section also required the caregiver to rate to what extent each need was satisfied by the services provided to them if they had received it before following a five-point Likert scale, with 1 denoting ‘not satisfy’ and 5 denoting ‘always satisfy’. Higher score indicated higher satisfaction with services received or vice versa. Part Two of PRNQ-C required the participants to rate their perceived importance of different kinds of psychiatric rehabilitation services following a five-point Likert scale, with 1 denoting ‘not important’ and 5 denoting ‘very important’. Higher score indicated higher importance of the psychiatric rehabilitation services or vice versa. The participants also needed to answer to what extent they satisfied with each kind of services if they had received it before following a five-point Likert scale, with 1 denoting ‘not satisfy’ and 5 denoting ‘always satisfy’. Higher score indicated higher satisfaction with the psychiatric rehabilitation service they received. Demographic information such as age, gender, educational level, marital status, living condition, employment status, and caregiving length were collected.

5.2.3. DATA COLLECTION

Written consent from each participant was obtained before data collection with clear explanation of the purpose and procedure of the study. Two trained assessors, a certified occupational therapist and a research assistant with a psychology background, conducted face to face interview for each participant. The interview was conducted at Yung Fung Shee Psychiatric Centre, and participating non-government organizations (NGOs) which included Richmond Fellowship of Hong Kong and The Hong Kong Family Link Mental Health Advocacy Association. The assessors were independent of the development of the PRNQ-C and were provided with training on the standardized administration of the instrument by the chief supervisor. Data collection process was coordinated by the certified occupational therapist.

5.2.4 DATA ANALYSIS

Statistical Package for the Social Science (SPSS) version 17.0 was used for data analysis. The demographic data of the 98 caregivers and the scores of PRNQ-C were summarized by descriptive and frequency statistics. T-test was used to compare the differences in mean scores of eight domains of perceived rehabilitation need of PRNQ-C between subgroups in terms of gender, living condition, and employment status of the samples. One-way analysis of variance test (ANOVA) was used to compare the differences in means scores of eight domains of PRNQ-C between subgroups in terms of age group, educational level, marital status, income and years of taking care of people with schizophrenia. Pearson’s correlation test and Spearman’s rho correlation test were used to analyze the correlation between the items in Part1 and Part2 of PRNQ-C.

5.3 RESULTS

5.3.1 DESCRIPTIVE STATISTICS

The descriptive statistics of Part One and Part Two of PRNQ-C are summarized in Table 6 and Table 7 respectively. There are fifty items in Table 6a and forty-five items in Table 6b. The difference was because some items were not appropriate in the part of satisfaction of perceived rehabilitation needs and the number of respondents of some of items in this section was zero. There were thirteen items in Table 7a and twelve items in Table 7b. The difference was due to the fact that there was no respondent in item 9 in the section of satisfaction of rehabilitation service.

The mean scores of stress management, societal and financial support, and knowledge on illness, caring skills, and relationship were perceived to be most important rehabilitation needs among all domains covered by this section. In the domain of stress management, the highest mean item scores belonged to item 42 “Reduce the worries over the patient’s future” and item 38 “Reduce the worries over unexpected problem of the patient” (Mean=4.41 and 4.37 respectively). In the domain of societal and financial support, item 10 “Provide the awareness of support” and item 17 “ Provide sufficient money for the expense of new medication” were the highest

(Mean=4.30 and 4.29 respectively). As to knowledge on illness, caring skills, and relationship, the mean score of item 30 “Increase caregiver’s knowledge of mental illness” and item 28 “Provide knowledge on differentiating the patient’s personalities from the symptoms” were the highest (Mean=4.39 and 4.38 respectively). On the whole, the mean item scores on importance of perceived rehabilitation needs were above three. Exceptions included item 49 “increase the type of leisure activities”, item 34 “reduce self-discrimination”, item 4 “reduce the waiting time for halfway house” and item 1 “reduce the influence on one’s work performance because of the phone calls made by the patient”, meaning that these items were perceived to be less important compared with other items.

In the section on satisfaction of perceived rehabilitation needs, the mean scores of all domains were between three and four. The highest domain score in this section was “reduce burden from supervising medication” (Mean=3.84) and the lowest was “reduced interruption of life and recognition of caregiver’s roles” (Mean=3.41). In the domain of “reduce burden from supervising medication”, the mean score of item 24 “reduce the influence on the relationship between caregiver and patient resulted from urging the patient to take medication” was the highest (Mean=4.15, N=13). In the domain of “reduced interruption of life and recognition of caregiver’s roles”, the mean score of item 16 “increase the right of managing the Comprehensive Social

Security Assistance (CSSA) allowance of the patients" was the lowest (Mean=3.38, N=13). The mean of all the items were above three, except the item 5. increase living space (Mean=2.75, N=4). This indicated caregivers were not satisfied with service in fulfilling their needs in living space. The number of participants to this section was relatively low. The item with the most respondents responded was item 14 "increase support by other mental health professionals apart from doctors" (N=30). Respondents for the items were few compared with the section of perceived importance. The number of respondents ranged from 3 to 30. Only six items had the number of respondents equal to 20 or above. There were twenty-three items with the number of respondents equal to ten or below and three items (item 29, 34 and 35) with no respondents at all.

In the section on importance of rehabilitation service, the mean scores of all items were above three, except item 10 "Qi-gong", item 12 "religious activity" and item 13 "yoga". That mean these leisure activities were not considered important for the caregivers. The highest mean score in this section was item 8. Hotlines (Mean=3.78). That mean hotline service e.g. suicide and family violence was considered important for the caregivers.

In the section of satisfaction of rehabilitation service, the mean of item 2 "psychological therapy" (N=4), item 3 "self-management education and training"

(N=6), item 4 “self-help organization” (N=13) and item 10 “Qi-gong” (N=9) were four or above. That mean those caregivers who received these services before were satisfied. The mean of item 7 “compassionate housing” (N=2) in this section was 1.5 only. That mean the caregivers were not satisfied with this rehabilitation service. Item 6 “CSSA allowance” had the most respondents (N=30). There were eight items with the respondents below ten. There was no respondent in item 9 “emergency housing”.

Table 6a. Descriptive Statistics of PRNQ—C(Importance of Perceived Rehabilitation Needs)

Importance of perceived rehabilitation needs (N=98)					
Domain	*Mean* of domain	*SD* of domain	Item	*Mean*	*SD*
Stress management	4.14	0.83	36. Reduce the apprehension of the change of condition of the patient	4.32	0.96
			38. Reduce the worries over unexpected problem of the patient	4.37	0.92
			39. Reduce the psychological burden due to the lack of understanding of the patient’s condition	3.91	1.18
			41. Obtain peer support and encouragement	4.24	1.10
			42. Reduce the worries over the patient’s future	4.41	0.90
			43. Reduce the worries over the patient’s safety	4.20	1.11
			44. Make time to take care of the patient’s daily life	3.86	1.20
			47. Reduce the difficulty in caretaking brought by the daily habit of the patient	3.82	1.26
Leisure and social life	3.21	1.02	18. Increase time for social life	3.35	1.24
			19. Reduce self isolation and social withdrawal	3.00	1.37
			20. Expand the circle of friends in which one is the centre of the circle	3.38	1.25
			21. Increase support and understanding from friends and thus expand one’s social network	3.59	1.30
			48. Increase the time for leisure activities	3.14	1.32
			49. Increase the type of leisure activities	2.93	1.25

			50. Increase the motivation for participating in leisure activities	3.07	1.32
Societal and financial support	4.12	0.75	6. Increase channels of seeking help	4.26	1.00
			7. Provide psychological counseling service	3.53	1.34
			8. Provide support catered for the needs of caregivers	4.11	0.98
			9. Provide information on identifying the kind of support required	4.21	0.88
			10. Provide the awareness of support	4.30	0.96
			14. Increase support by other mental health professionals apart from doctors	4.11	1.11
			17. Provide sufficient money for the expense of new medication	4.29	1.09
Reduce burden from supervising medication	3.77	0.99	11. Reduce the burden of urging patient to take medication	3.72	1.40
			12. Reduce the worries on the patient's taking of medication	3.83	1.33
			13. Reduce the burden brought by the side effect of medication of the patient	4.13	1.11
			24. Reduce the influence on the relationship between caregiver and patient resulted from urging the patient to take medication	3.11	1.54
			40. Reduce the frustration brought by the fluctuation of the patient's condition	4.07	1.05
Knowledge on illness, caring skills, and relationship	4.16	0.76	22. Improve relation with other family members	3.69	1.31
			23. Increase the acceptance of the patient by the family	3.96	1.28
			25. Enhance communication skills with the patient	4.08	1.03
			26. Accept some of the behaviors of the patient	4.16	0.99
			27. Strengthen communication with the patient and build a mutual trust relation	4.33	0.92
			28. Provide knowledge on differentiating the patient's personalities from the symptoms	4.38	0.88
			30. Increase caregiver's knowledge of mental illness	4.39	0.80
			31. Be available to certified health or rehabilitation professionals (e.g., psychologist, occupational therapist, etc.) on answering enquiries	4.35	0.85
			32. Increase channels of obtaining information	4.12	1.00
			45. Strengthen caring skills	4.08	1.08
			46. Understand the proper attitude of care taking	4.26	0.97
Reduced discrimination	3.31	1.03	2. Reduce discrimination against family members of mental illness patient	3.37	1.39
			33. Reduce discrimination by the society	3.90	1.27
			35. Reduce the deprivation for being family member of mental illness patient	3.16	1.45

			34. Reduce self-discrimination	2.80	1.44
Work and accommodation	3.56	0.97	3. Able to handle one’s work and take care of the patient at the same time	3.98	1.25
			4. Reduce the waiting time for halfway house	2.81	1.57
			5. Increase living space	3.63	1.42
			37. Reduce the pressure on working and taking care of the patient at the same time	3.82	1.40
Reduced interruption of life and recognition of caregiver’s roles	3.24	1.00	1. Reduce the influence on one’s work performance because of the phone calls made by the patient	2.51	1.22
			15. Reduce financial reserve for the patient	3.86	1.29
			16. Increase the right of managing the Comprehensive Social Security Assistance (CSSA) allowance of the patients	3.35	1.47
			29. Change the conception that the caregiver is responsible for the illness of the patient	3.23	1.43

Table 6b. Descriptive Statistics of PRNQ—C(Satisfaction of Perceived Rehabilitation Needs)

Satisfaction of perceived rehabilitation needs						
Domain	Mean of domain	*SD* of domain	Item	N=number of respondents to the item	Mean	*SD*
Stress management	3.66	1.02	36. Reduce the apprehension of the change of condition of the patient	9	3.78	0.97
			38. Reduce the worries over unexpected problem of the patient	8	3.63	0.92
			39. Reduce the psychological burden due to the lack of understanding of the patient’s condition	7	3.71	1.11
			41. Obtain peer support and encouragement	5	3.80	0.84
			42. Reduce the worries over the patient’s future	8	3.88	0.64
			43. Reduce the worries over the patient’s safety	9	3.67	1.22
			47. Reduce the difficulty in caretaking brought by the daily habit of the patient	5	4.00	0.71
Leisure and social life	3.79	0.97	18. Increase time for social life	10	4.10	0.99
			19. Reduce self isolation and social withdrawal	8	3.88	0.64
			20. Expand the circle of friends in which one is the centre of the circle	8	3.88	1.13

			21. Increase support and understanding from friends and thus expand one’s social network	9	3.56	1.13
			49. Increase the type of leisure activities	6	4.67	0.52
			50. Increase the motivation for participating in leisure activities	7	4.43	0.79
Societal and financial support	3.78	0.96	6. Increase channels of seeking help	26	3.85	0.93
			7. Provide psychological counseling service	8	4.12	0.84
			8. Provide support catered for the needs of caregivers	12	4.17	0.84
			9. Provide information on identifying the kind of support required	12	4.00	1.04
			10. Provide the awareness of support	20	3.65	1.04
			14. Increase support by other mental health professionals apart from doctors	30	3.60	1.28
			17. Provide sufficient money for the expense of new medication	18	4.17	1.04
Reduce burden from supervising medication	3.84	1.03	11. Reduce the burden of urging patient to take medication	14	4.07	1.14
			12. Reduce the worries on the patient’s taking of medication	12	4.08	1.24
			13. Reduce the burden brought by the side effect of medication of the patient	10	3.70	0.82
			24. Reduce the influence on the relationship between caregiver and patient resulted from urging the patient to take medication	13	4.15	0.90
			40. Reduce the frustration brought by the fluctuation of the patient’s condition	13	3.77	1.01
Knowledge on illness, caring skills, and relationship	3.57	1.08	22. Improve relation with other family members	4	3.75	1.26
			23. Increase the acceptance of the patient by the family	1	5.00	
			25. Enhance communication skills with the patient	12	3.75	1.14
			26. Accept some of the behaviors of the patient	19	3.37	1.07
			27. Strengthen communication with the patient and build a mutual trust relation	11	3.82	1.25
			28. Provide knowledge on differentiating the patient’s personalities from the symptoms	15	3.27	1.49
			30. Increase caregiver’s knowledge of mental illness	23	3.83	1.03
			31. Be available to certified health or rehabilitation professionals (e.g., psychologist, occupational therapist, etc.) on answering enquiries	27	3.96	1.19
			32. Increase channels of obtaining information	17	3.53	1.07
			45. Strengthen caring skills	9	3.56	1.42
			46. Understand the proper attitude of care taking	10	3.20	1.32

Reduced discrimination	3.77	1.13	2. Reduce discrimination against family members of mental illness patient	9	4.00	1.23
			33. Reduce discrimination by the society	3	3.33	0.58
Work and accommodation	3.75	1.09	3. Able to handle one’s work and take care of the patient at the same time	10	4.40	0.52
			5. Increase living space	4	2.75	1.71
			37. Reduce the pressure on working and taking care of the patient at the same time	9	4.00	0.87
Reduced interruption of life and recognition of caregiver’s roles	3.41	1.11	15. Reduce financial reserve for the patient	23	3.48	1.08
			16. Increase the right of managing the Comprehensive Social Security Assistance (CSSA) allowance of the patients	13	3.38	1.39

Table 7a. Descriptive Statistics of PRNQ—C(Importance of Rehabilitation Services)

Importance of rehabilitation services (N=98)					
Services	*Mean* of service category	*SD* of service category	Item	*Mean*	*SD*
Family rehab	3.67	1.25	1. Family Therapy	3.67	1.25
Psychotherapy	3.45	1.35	2. Psychological Therapy	3.45	1.35
Self management	3.54	1.29	3. Self-management education and training	3.54	1.29
Social activity	3.24	1.14	4. Self-help organization	3.27	1.22
			5. Day training and activity centre	3.21	1.19
Social welfare	3.37	1.40	6. CSSA Allowance	3.52	1.52
			7. Compassionate Housing	3.21	1.62
Emergency services	3.57	1.26	8. Hotlines (e.g. suicide and family violence)	3.78	1.34
			9. Emergency housing	3.37	1.47
Others	2.81	0.92	10. Qi-gong	2.77	1.31
			11. Activity on the prevention of discrimination	3.32	1.36
			12. Religious activity	2.97	1.41

			13. Yoga	2.18	1.16

Table 7b. Descriptive Statistics of PRNQ—C(Satisfaction of Rehabilitation Services)

Satisfaction of rehabilitation services						
Services	*Mean* of service category	*SD* of service category	Item	N=number of respondents to the item	Mean	*SD*
Family rehab	3.67	1.37	1. Family Therapy	6	3.67	1.37
Psychotherapy	4.50	0.58	2. Psychological Therapy	4	4.50	0.58
Self management	4.00	0.89	3. Self-management education and training	6	4.00	0.89
Social activity	3.94	0.87	4. Self-help organization	13	4.00	1.00
			5. Day training and activity centre	13	3.92	0.86
Social welfare	3.76	1.24	6. CSSA Allowance	30	3.87	1.14
			7. Compassionate Housing	2	1.50	0.71
Emergency services	3.63	1.69	8. Hotlines (e.g. suicide and family violence)	8	3.62	1.69
Others	3.99	1.09	10. Qi-gong	9	4.44	0.88
			11. Activity on the prevention of discrimination	1	3.00	NA
			12. Religious activity	25	3.88	1.13
			13. Yoga	3	3.33	0.58

5.3.2 DEMOGRAPHIC ANALYSIS

Table 8a, 8b, 8c and 8d present the mean scores of the eight domains of perceived rehabilitation need in relation to the socio-demographic characteristics of the respondents and the results of comparison between these demographic subgroups.

There was a significant difference between the living condition in the domain of reduced burden from supervising medication, and work and accommodation (t=-2.15, p=.04 and t=-2.15, p=.03) respectively. Those caregivers not living with people with schizophrenia scored significantly higher in both of the domains. This indicated that those caregivers not living with the clients had a greater need in reducing burden from supervising medication of the client. Also they had more need in handling their work and taking care of client at the same time. In addition, they had more accommodation need. Those caregivers who was unemployed scored significantly higher in the domain of reduced burden from supervising medication and reduced discrimination (t=2.49, p=.02 and t=2.07, p=.04) respectively. This indicated that caregivers who were unemployed had greater need in supervising medication of the clients and reducing discrimination by the society. There were no significant differences between caregiver subgroups in terms of gender, age, educational level, marital status, income and years of taking care of people with schizophrenia.

Table 8a. Results of t-test and ANOVA with the 8 domains of the perceived rehabilitation need in terms of gender and age of caregivers

	Gender N=98				Age N=98						
	Male (n=38)	Female (n=60)	*t*-value	*p*-value	18-25 (n=3)	26-35 (n=11)	36-45 (n=14)	46-55 (n=26)	56 or above (n=44)	*F*-value	*p*-value
Stress	4.01	4.19	-0.75	0.46	3.83	3.99	4.06	4.15	4.21	0.30	0.88
Leisure	3.39	3.10	1.39	0.17	3.67	2.73	3.51	2.99	3.32	1.44	0.23
Societal	4.14	4.10	0.29	0.77	3.90	3.96	3.99	4.03	4.26	0.76	0.55
Medication	3.64	3.86	-1.04	0.30	3.93	3.69	3.60	3.55	3.97	0.88	0.48
Knowledge	4.12	4.19	-0.45	0.65	4.33	3.99	8.34	4.15	4.30	1.20	0.32
Reduced discrimination	3.33	3.29	0.17	0.86	3.83	3.18	3.32	3.24	3.34	0.26	0.90
Work	3.55	3.56	-0.05	0.96	3.33	3.30	3.34	3.64	3.66	0.58	0.68
Reduced interruption	3.36	3.16	0.93	0.36	2.75	3.20	3.25	3.10	3.36	0.46	0.76

An asterisk * indicates statistical significant less than 0.05

Table 8b. Results of t-test and ANOVA with the 8 domains of the perceived rehabilitation need in terms of educational level and marital status of caregivers

	Educational Level N=98						Marital status N=98					
	Illiterate (n=6)	Primary (n=37)	Secondary (n=48)	Tertiary or above (n=7)	*F*-value	*p*-value	Single (n=14)	Married (n=69)	Divorced (n=8)	Widowed (n=7)	*F*-value	*p*-value
Stress	4.15	4.11	4.19	3.93	0.21	0.89	3.81	4.16	4.09	4.59	1.46	0.23
Leisure	2.90	3.14	3.35	2.86	0.84	0.48	3.06	3.22	2.98	3.63	0.63	0.60
Societal	4.12	4.01	4.20	4.06	0.46	0.72	4.06	4.10	4.07	4.47	0.56	0.64
Medication	3.47	3.79	3.83	3.60	0.30	0.83	3.27	3.85	3.60	4.20	1.90	0.14
Knowledge	4.14	4.15	4.25	3.66	1.24	0.30	3.85	4.19	4.13	4.53	1.39	0.25
Reduced discrimination	3.25	3.20	3.45	2.93	0.78	0.51	3.07	3.26	3.81	3.68	1.24	0.30
Work	3.71	3.36	3.69	3.54	0.84	0.48	3.39	3.59	3.34	3.79	0.42	0.74
Reduced interruption	3.63	3.12	3.28	3.25	0.48	0.70	3.07	3.23	3.66	3.18	0.60	0.62

An asterisk * indicates statistical significant less than 0.05

Table 8c. Results of t-test and ANOVA with the 8 domains of the perceived rehabilitation need in terms of employment status and income of caregivers

	Employment Status N=98				Income N=38						
	Employed (n=38)	Unemployed (n=60)	*t*-value	*p*-value	5000 or below (n=7)	5001-7000 (n=11)	7001-10000 (n=6)	10001-15000 (n=3)	15001 or above (n=11)	*F*-value	*p*-value
Stress	3.91	4.28	-2.00	0.05	4.21	3.69	4.38	3.46	3.82	0.78	0.55
Leisure	2.98	3.35	-1.78	0.08	3.43	2.44	3.26	2.81	3.13	1.14	0.36
Societal	4.06	4.15	-0.58	0.57	4.47	3.62	4.60	3.43	4.12	2.18	0.09
Medication	3.44	3.98	-2.49	0.02*	4.23	3.35	3.27	2.20	3.47	1.81	0.15
Knowledge	3.98	4.28	-1.76	0.08	4.45	3.47	4.27	2.76	4.09	2.36	0.07
Reduced discrimination	3.04	3.48	-2.07	0.04*	2.86	2.91	3.25	2.67	3.27	0.31	0.87
Work	3.57	3.55	0.11	0.91	4.11	3.34	3.63	2.83	3.64	1.01	0.42
Reduced interruption	3.29	3.20	0.41	0.68	3.18	2.98	4.04	3.25	3.27	1.12	0.36

An asterisk * indicates statistical significant less than 0.05

Table 8d. Results of t-test and ANOVA with the 8 domains of the perceived rehabilitation need in terms of living condition and years of taking care of people with schizophrenia of caregivers

	Living condition N=98				Years of taking care of people with schizophrenia N=98					
	Live with pt (n=76)	Not live with pt (n=22)	*t*-value	*p*-value	2 yrs or below (n=14)	2-5 yrs (n=23)	5-10 yrs (n=18)	10 yrs or above (n=43)	*F*-value	*p*-value
Stress	4.11	4.23	-0.56	0.57	4.26	3.91	4.13	4.23	0.86	0.46
Leisure	3.17	3.33	-0.64	0.53	3.06	3.14	2.97	3.39	0.92	0.43
Societal	4.04	4.36	-1.78	0.08	4.26	3.93	4.01	4.22	1.03	0.38
Medication	3.68	4.09	-2.15	0.04*	3.56	3.66	3.41	4.06	2.37	0.08
Knowledge	4.14	4.25	-0.62	0.54	4.38	4.09	4.06	4.18	0.54	0.66
Reduced discrimination	3.35	3.15	0.82	0.42	3.13	2.97	3.18	3.60	2.29	0.08
Work	3.45	3.94	-2.15	0.03*	3.18	3.41	3.49	3.79	1.78	0.16
Reduced interruption	3.18	3.40	-0.85	0.40	3.20	3.09	3.08	3.40	0.67	0.57

An asterisk * indicates statistical significant less than 0.05

5.3.3 RELATIONSHIP BETWEEN IMPORTANCE AND SATISFACTION AMONG PERCEIVED REHABILITATION NEEDS AND SERVICES

Table 9 summarizes the correlation results between the perceived rehabilitation need and need satisfaction of items in part-one of PRNQ-C. In the domain on stress management, significant correlation was found in item 42 (p-value=0.005): reduce the worries over the patient’s future. In the domain of societal and financial support, significant correlation was found in item 8(p-value=0.04): provide support catered for the needs of caregivers and item 7(p-value=0.01): provide psychological counseling service. In the domain of reduced burden from supervising medication, significant correlation was found in item 24(p-value=0.03): reduce the influence on the relationship between caregiver and patient resulted from urging the patient to take medication. In the domain of knowledge on illness, caring skills, and relationship, significant correlation was found in item 31(p-value=0.01): be available to certified health or rehabilitation professionals (e.g., psychologist, occupational therapist, etc.) on answering enquiries. In the domain of reduced discrimination, significant correlation was found in item 33(p-value<0.001): reduce discrimination by the society. In items 42, 7, 8, 31 and 33, there were significant positive correlation between the perceived importance and the satisfaction of the perceived rehabilitation needs. High score on the satisfaction of the needs went together with high score of the perceived importance of the needs. In item 24 “reduce the influence on the relationship between caregiver and patient resulted from urging the patient to take medication”, a negative correlation was found. This means that the higher the score of the importance of this need, the lower the score of its satisfaction or vice versa.

Table 10. summarizes the correlation between the importance of rehabilitation service and service satisfaction. Significant correlation were found in item 8.hotline(p-value=0.04), item 10.qi-gong(p-value<0.01) and item 12.religious activity(p-value=0.003). This showed that if the score of importance of the hotline service, qi-gong and religious activity were high, the satisfaction of these items would be also high or vice versa.

Table 9. The Correlation between the Importance of Perceived Rehabilitation Need and Need Satisfaction

Domain/ Item	N=number of respondents to the item	Correlation Coefficient	p-value
Stress management/			
36. Reduce the apprehension of the change of condition of the patient	9	0.29	0.45
38. Reduce the worries over unexpected problem of the patient	8	-0.41	0.31
39. Reduce the psychological burden due to the lack of understanding of the patient's condition	7	-0.46	0.30
41. Obtain peer support and encouragement	5	0.30	0.62
42. Reduce the worries over the patient's future	8	0.87	<0.01*
43. Reduce the worries over the patient's safety	9	0.22	0.57
47. Reduce the difficulty in caretaking brought by the daily habit of the patient	5	0.00	1
Leisure and social life/			
18. Increase time for social life	10	-0.07	0.85
19. Reduce self isolation and social withdrawal	8	-0.37	0.37
20. Expand the circle of friends in which one is the centre of the circle	8	0.12	0.78
21. Increase support and understanding from friends and thus expand one's social network	9	0.22	0.57
49. Increase the type of leisure activities	6	-0.11	0.83
50. Increase the motivation for participating in leisure activities	7	-0.24	0.60
Societal and financial support/			
6. Increase channels of seeking help	26	-0.01	0.94
7. Provide psychological counseling service	8	0.84	0.01*
8. Provide support catered for the needs of caregivers	12	0.59	0.04*
9. Provide information on identifying the kind of support required	12	0.39	0.21
10. Provide the awareness of support	20	0.32	0.16
14. Increase support by other mental health professionals apart from doctors	30	0.05	0.78
17. Provide sufficient money for the expense of new medication	18	0.19	0.44
Reduced burden from supervising medication/			
11. Reduce the burden of urging patient to take medication	14	0.22	0.44
12. Reduce the worries on the patient's taking of medication	12	0.57	0.06
13. Reduce the burden brought by the side effect of medication of the patient	10	0.31	0.38
24. Reduce the influence on the relationship between caregiver and	13	-0.59	0.03*

patient resulted from urging the patient to take medication			
40. Reduce the frustration brought by the fluctuation of the patient's condition	13	-0.21	0.48
Knowledge on illness, caring skills, and relationship/			
22. Improve relation with other family members	4	0.00	1.00
25. Enhance communication skills with the patient	12	0.46	0.13
26. Accept some of the behaviors of the patient	19	0.42	0.07
27. Strengthen communication with the patient and build a mutual trust relation	11	0.37	0.26
28. Provide knowledge on differentiating the patient's personalities from the symptoms	15	0.04	0.89
30. Increase caregiver's knowledge of mental illness	23	0.12	0.58
31. Be available to certified health or rehabilitation professionals (e.g., psychologist, occupational therapist, etc.) on answering enquiries	27	0.49	0.01*
32. Increase channels of obtaining information	17	-0.37	0.14
45. Strengthen caring skills	9	-0.05	0.9
46. Understand the proper attitude of care taking	10	0.28	0.44
Reduced Discrimination/			
2. Reduce discrimination against family members of mental illness patient	9	0.36	0.34
33. Reduce discrimination by the society	3	1.00	<0.01*
Work and Accommodation/			
3. Able to handle one's work and take care of the patient at the same time	10	0.28	0.43
5. Increase living space	4	-0.63	0.37
37. Reduce the pressure on working and taking care of the patient at the same time	9	0.00	1.00
-Reduced Interruption of Life and Recognition of Caregiver's Roles/			
15. Reduce financial reserve for the patient	23	0.28	0.2
16. Increase the right of managing the Comprehensive Social Security Assistance (CSSA) allowance of the patients	13	-0.02	0.95

An asterisk * indicates statistical significant less than 0.05

Table 10. The Correlation between the Importance of Rehabilitation Service and Service Satisfaction

Service/ item	N=number of respondents to the item	Correlation Coefficient	p-value
Family rehab/			
1. Family Therapy	6	0.35	0.49
Psychotherapy/			
2. Psychological Therapy	4	NA	NA
Self management/			
3. Self-management education and training	6	0.00	1.00
Social activity/			
4. Self-help organization	13	0.54	0.06
5. Day training and activity centre	13	0.36	0.23
Social welfare/			
6. CSSA Allowance	30	0.17	0.38
7. Compassionate Housing	2	NA	NA
Emergency services/			
8. Hotlines (e.g. suicide and family violence)	8	0.73	0.04*
Others/			
10. Qi-gong	9	0.95	<0.01*
11. Activity on the prevention of discrimination	1	NA	NA
12. Religious activity	25	0.58	0.003*
13. Yoga	3	0.87	0.33

An asterisk * indicates statistical significant less than 0.05

5.3.4 THE CORRELATION BETWEEN IMPORTANCE OF PERCEIVED REHABILITATION NEEDS AND SERVICES

Table 11 summarizes the correlation results between the importance of perceived rehabilitation needs and the perceived importance of rehabilitation services (N=98). In the domain of stress management; leisure and social life; societal and financial support; knowledge on illness, caring skills, and relationship; work and accommodation; and reduced interruption of life and recognition of caregiver’s roles, significant correlations were found with the service of family therapy, psychotherapy, self-management, social activity, social welfare, emergency services and others (p-value<0.05). In the domain on reduce burden from supervising medication, significant correlations were found with the service of family therapy, psychotherapy, self-management, social activity, emergency services and others (p-value<0.05). In the domain on reduce discrimination, significant correlation were found with the service of psychotherapy, self-management, social activity, social welfare, emergency services and others (p-value<0.05). The results indicated that almost all of the perceived rehabilitation needs were significantly positively correlated with perceived importance of the rehabilitation services.

Table 11. The Correlation between the Importance of Perceived Rehabilitation Need and Importance of Rehabilitation Service

N = 98								
		Domain of services						
Domain of needs		family_therapy	psycho	self_mx	social_act	welfare	emergency	others
Stress management	Pearson Correlation	.356**	.414**	.502**	.451**	.441**	.482**	.496**
	p-value	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01
Leisure and social life	Pearson Correlation	.328**	.467**	.518**	.553**	.464**	.466**	.489**
	p-value	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01
Societal and financial support	Pearson Correlation	.425**	.503**	.513**	.424**	.225*	.323**	.395**
	p-value	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01
Reduce burden from supervising	Pearson Correlation	.260**	.271**	.358**	.358**	0.187	.319**	.342**
	p-value	0.01	0.01	<0.01	<0.01	0.07	<0.01	<0.01

medication								
Knowledge on illness, caring skills, and relationship	Pearson Correlation	.564**	.464**	.575**	.522**	.296**	.416**	.465**
	p-value	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01	<0.01
Reduced discrimination	Pearson Correlation	0.172	.215*	.270**	.331**	.308**	.378**	.433**
	p-value	0.09	0.03	0.01	<0.01	<0.01	<0.01	<0.01
Work and accommodation	Pearson Correlation	.296**	.282**	.319**	.245*	.431**	.434**	.417**
	p-value	<0.01	0.01	<0.01	0.02	<0.01	<0.01	<0.01
Reduced interruption of life and recognition of caregiver's roles	Pearson Correlation	.211*	.285**	.246*	.203*	.402**	.206*	.354**
	p-value	0.04	<0.01	0.02	0.05	<0.01	0.04	<0.01

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

5.4 DISCUSSION

5.4.1 PERCEIVED IMPORTANCE OF NEED OF CAREGIVERS

The findings show that the need levels among Chinese caregivers for patients with schizophrenia are high. This is consistent with the previous studies (Pearce, McGovern & Barrowclough, 2005; Chien & Norman, 2002). This may be explained by the cohesiveness of Chinese families which make members more dependent on each other for emotional and social support (Pearson & Lam, 2000; Chien et al.,2007). Chinese families are eager to persistently provide physical and psychological support to clients with severe mental illness and offer them the best possible care (McCubbin & McCubbin, 1993). Nevertheless, studies found that caregivers received little recognition for their work and their needs were underestimated by the health professionals (Mueser et al, 1992; Chan, 2011). The high levels of the eight domains of needs rated by the caregivers may revealed that most of them viewed their needs being a multidimensional in terms of their mental health, physical condition, social life and financial status as a result of lacking of personal, financial, and emotional resource provided for them (Chien et al., 2007; Chan, 2011).

Factors that were considered more important based on the survey included “Stress management”, “Knowledge on illness, caring skills, and relationship” and “Societal and financial support”. Among all these factors, caregivers regarded “Knowledge on illness, caring skills, and relationship” as the most important perceived need. The finding was consistent with the current literature that caregivers expressed high level of need in the area of information about the mental illness (Pearce et al., 2005; Chien et al., 2003). Caregivers who live in Hong Kong often show a lack of knowledge about mental illness (Ma & Yip, 1997). Studies also suggested that family may experience less burden if they are adequately informed and supported (Addington at al., 2003; Sin et al., 2005). This may be explained for the high level of need on knowledge of the illness. In the domain of “Stress management”, caregivers showed the need to manage their stress and thus alleviate related physical and psychological symptoms. First, they need reassurance over patient’s future. Caregivers were commonly found to worry about the patient’s health, their own future and finance (Thornicroft et al., 2004, Cleary et al., 2006). Second, caregivers viewed the ways of coping with patients' symptoms and behavior and strategies for solving daily problem were very important (Chien & Norman, 2003). The perceived need of "Societal and financial support" was rated high in this study. This reflected that the accessibility and availability of support, financial resources and mental health professional in the community was perceived to be important by caregivers. Furthermore, support provided by other mental health professionals other than doctors were important for the caregivers and which was in line with the work of Tesslerr et al. (1991).

The least important perceived need identified were "Leisure and social life" and "Reduced interruption of life and recognition of caregiver's roles". Chinese families caregiver tried to provide the best care for their relatives with schizophrenia and spent most of their time in caregiving, so that they may neglect the need of leisure and social life (McCubbin & McCubbin, 1993).

5.4.1.1 SOCIO-DEMOGRAPHIC CHARACTERISTIC OF CAREGIVER

The significant differences of the socio-demographic variables of families and the caregivers' needs in this study indicated that caregivers with certain demographic characteristic had higher level of some needs. The unemployed caregivers were found to have a higher level of perceived needs to reduce burden from supervising medication and reduced discrimination. Hong Kong Caregivers who were unemployed may face a range of stress such as financial, discrimination and psychological problems. They may find it embarrassing to let their friends or neighbors know that they were unemployed because of the need to take care of relatives with schizophrenia. They are afraid of being discriminated as people with severe mental illness were severely stigmatized in Hong Kong (Tsang et al., 2003). This finding was in line with the previous finding that caregivers with low social position had more frequent stressful experiences and high feeling of distress (Bulger at al. 1993). Unemployed caregivers are likely to closer contact with client and have greater burden associated with the worries of health concerns. Their tendency to seek help and the needs for health services will be higher (Tsang et al., in press; Bland, Newman & Orn, 2007). In previous studies on caregiver burden, economic hardship, the need for constant supervision and housework was found to be the most important aspect of the objective burden factor (Baronet, 1999). Caregivers who are not living with the relatives with schizophrenia obviously have a higher perceived need on reducing burden from supervising medication, and work and accommodation. They probably need to work and take care of client simultaneously. As a result, they need specific services to relieve their burden in supervising medication of the client and caregiving, so that their responsibility could be shared out even though they were not living with the client.

Caregivers' age, gender, educational level and years of taking care of people with schizophrenia were found not related to the perceived needs in the present study. The small sample size may account for the lack of significance of findings with the carers' demographics. The lack of significant difference of perceived need among the age groups in the present study may likely due to the reason that more than two-thirds of the caregivers recruited were aged forty-six or above, so that the need of the younger caregivers may not be truly reflected in this study. A review on our findings and those of previous studies suggest that relationship between demographic variables and caregivers' burden is not conclusive. Studies reported that older caregivers perceived less care burden, either because they have greater tolerance, improved coping strategy, decreased expectation or they resign from caregiving (Magliano et al., 2000; Ran et al., 2003; Perlick et al., 2006). Some however have contradictory findings that older caregivers have greater perceived burden due to poorer health condition (Chien et al., 2007). Furthermore, a study of caregivers of the mentally ill in Chinese society found that the age of caregivers was not related to the level of burden (Fan & Chen, 2011). Even though the studies conducted in Chinese families, no consistent results could be generated (Chien et al., 2007; Ran et al., 2003.).

In terms of educational level, our study also has different findings compared with the literature. Caregivers with higher educational level were found to have higher perceived needs (Yeh et al., 2008; Chien & Norman, 2003). The highly educated group of caregivers seems to have a more aggressive and/or active attitude towards patient care (Yeh et al., 2008). While the less-educated caregivers were concerned more about the advice on intimate relationships for the patient. However, a study found that care burden was not related to caregivers' educational attainment (Fan & Chen, 2011). In this study, most of the respondents attained only primary or secondary educational level, the number of respondents with higher level of education was low (N=7). This may be the reason why differences among the educational levels were not detected.

5.4.2 THE IMPORTANCE AND SATISFACTION OF PERCEIVED NEED OF CAREGIVERS

The correlation between the importance of need and satisfaction of needs reflected the service gap in the existing psychiatric rehabilitation service. The negative correlation indicated a lack of services in fulfilling the needs of the caregivers. There was a discrepancy between importance and satisfaction in carers, and it may be due to service inadequacy, unawareness of services or unwillingness to use the services. The results showed that only six items in various domains were found to be significantly correlated between perceived importance and satisfaction of needs. This suggests that there may not be an overall correlation between the perceived importance and their satisfaction to the needs by caregivers. However, the relationship between perceived importance and satisfaction depends on individual items.

The items that were positively correlated included “reduce the worries over the patient’s future”, “provide support catered for the needs of caregivers”, “provide psychological counseling service”, “be available to certified health or rehabilitation professionals (e.g., psychologist, occupational therapist, etc.) on answering enquiries”, and “reduce discrimination by the society”.

In the present study, the domain on “Knowledge on illness, caring skills, and relationship” was perceived to be the most important among caregivers of people with schizophrenia. However, correlational analysis between the importance and the satisfaction of perceived needs found that there was one item “Be available to certified health or rehabilitation professionals (e.g., psychologist, occupational therapist, etc.) on answering enquiries” had significantly positive relation. The mean score of this item is high (Mean=4.35) which means that the caregivers found this specific need important and at the same time felt satisfied with the service they received. There were twenty seven caregivers who had received the services provided by mental health professionals staff. This finding was in line with the previous study which stated that majority of caregivers were satisfied with the outcome of contacts with mental health professionals and ranked “more communications with professionals” as their greatest need. (Tessler, Gamacho & Fisher, 1991; Biegel, Song & Milligan, 1995). Fortunately, this general finding applies also to Hong Kong. The further suggests that although many of the respondents may have not direct contacts with mental health professionals, the luckier minority who actually had contacts with them found their services useful. This also suggests that mental health professionals in Hong Kong are of high quality. But professional contacts are only restricted a small group of caregivers. Apart from this item, there was no relationship found between the importance and satisfaction in other items of this domain. In the same domain, caregivers showed much concern in the item of “Increase caregiver’s knowledge of mental illness” and Provide knowledge on differentiating the patient’s personalities from the symptoms. According to Ma et al. (1997) found that caregivers who live in Hong Kong with traditional Chinese culture and conceptualization often show a lack of knowledge about mental illness such as the biological attribution of schizophrenia (Chien at al., 2007). The severity of the symptoms of people with schizophrenia was an important relevant variable on the impact of caregiver burden. The positive symptoms of schizophrenia often caused a higher level of caregivers’ burden and the prolonged course of negative symptom would cause a long-term burden for the caregivers. (Hou et al., 2008). Caregivers were not satisfied with the services of education on knowledge on mental illness and it was in line with previous studies reported that caregivers have been complained about receiving insufficient information and inadequate practical advice from staff (Leavey et al., 1997; Wray, 1994).

This study found that caregivers expressed a high level of need in the domain of "Stress management" especially in the item "reducing the worries over patient's future" (Mean=4.41). There was a significant and positive correlation between the importance and satisfaction of this item. This result reflected that caregivers were satisfied with the service to resolve their concern over patient's future. However, there were only eight respondents who had actually received this kind of service. This again suggests that services to satisfy their need in this aspect are limited. Sincerity, loyalty, filial piety, and benevolence towards family members have been frequently reported to influence Chinese families' value and beliefs of caregiving (Chou, LaMontagne & Hepworth, 1999). Chinese families tried to provide the best care for their relatives with mental illness and not only concern at the early stage of the illness but rather the prolonged course of the illness. Wong (2007) suggested that Chinese people tend to reply on interfamilial coping and maintained a long-term commitment on caregiving.

The rehabilitation service to reduce their concern over patient’s future should therefore be strengthened. In this domain, caregivers also concerned very much on the item “Reduce the worries over unexpected problem of the patient”. Unfortunately, no significant correlation was found between its importance and satisfaction. Caregivers are often annoyed by the unpredicted and bizarre behavior of patients (Leff, 1994). There is a significant interrelation between the patients’ behavior and the degree of the caregivers’ burden. This indicated that providing rehabilitation service on handling the behavioral problems of patient may in turn lower the burden of the caregivers. Unfortunately, both the quantity and quality of services to satisfy this need are below the expectation levels.

In the domain on “Societal and financial support”, significant and positive correlation was found in the item “Provide psychological counseling service” (Mean=3.53) and “Provide support catered for the needs of caregivers” (Mean=4.11). Caregivers were satisfied with the psychological counseling services and support catered for their needs. But there were only a few respondents (N=8 to 12) that had actually received this kind of rehabilitation services. This finding indicated that more counseling service and tailor-made support service are necessary. Furthermore, caregivers found that “Provide the awareness of support” (Mean=4.30), “Increase channels for seeking help” (Mean=4.26), and “Increase support by other mental health professionals apart from doctors” (Mean=4.11) were very important. However, the results of present study showed that caregivers were dissatisfied with the existing service in fulfilling these needs in these areas. Findings indicated that caregivers need support and help seeking channels in the community. This is in line with the previous studies which showed that the needs and concerns of the caregivers were always left unmet by health professionals (Chien & Norman, 2003). The needs of caregivers for certain kinds of information about patients’ illness and to be informed of available mental health care benefits and services were underestimated (Mueser at al., 1992). Caregivers rated highly in the item “Providing sufficient money for the expense of new medication”. But this need could not be satisfied. Financial support was important for the caregivers as they often forego employment in order to take care of patient (Dyck et al., 1999). The poor financial status in family may further increased the distress and negative consequences of the caregivers (Chien et al, 2007). Therefore, more community support and financial resources should be provided for the caregivers.

In the domain on “Reduced discrimination”, significant and positive correlation between the importance and satisfaction was found in the item “Reduce discrimination by the society” (Mean=3.90). Caregivers expressed discrimination by the public. This is consistent with the findings of earlier studies that stigma toward mental illness is still a global phenomenon and it is related to burden in caregiving (Chan, 2011; Tsang et al., 2003; Yeh et al., 2008, Chien et al., 2007). In traditional Chinese culture, having family members with mental illness could lead to the whole family being seen as inferior (Tsang et al., 2003). Studies also revealed accusation against the family for causing the illness as a contributing factor to the rejection and social isolation of the caregivers (Kuipers et al., 1992, Lefley, 1992). Social stigma on mental illness discourages caregivers from seeking help and may result in less favorable social support. Although a positive correlation was found in this item, only three caregivers had ever received services to help them reduce social discrimination. The finding demonstrated that the anti-stigma campaign was severely inadequate. This needs to be taken into account for future policy development.

In the domain on “Reduced burden from supervising medication”, the importance and satisfaction of “Reduce the influence on the relationship between caregiver and patient resulted from urging the patient to take medication” was significantly but negatively correlated. The means of the importance and satisfaction of this item was 3.72 and 4.07 respectively. This suggests that the needs of caregivers in this aspects was already satisfied so that they expressed lesser concern but with high satisfaction in this area. However, the number of respondent in this item was only 14, this may not be representative to the population.

One point we need to take into consideration when interpreting the results is that the respondent rate to the satisfaction of these items were relatively low which ranged only from 3 to 30. First, the generalizability of the results is limited. Second, this suggests that the availability of rehabilitation services to satisfy their various rehabilitation needs in general were very limited.

5.4.3 THE IMPORTANCE AND SATISFACTION OF REHABILITATION SERVICE OF CAREGIVERS

The rehabilitation services perceived to be the most important were “family rehabilitation” and “emergency service”. Previous studies found that family interventions were found important in the caregivers (Chan, 2011; Pearce et al., 2005). Caregivers in Hong Kong found that psychoeducation program could increase their knowledge of mental illness and thus improve the capacity of monitoring their relatives’ symptoms or initiate more collaborative interaction with professionals in their treatment (Chan et al., 2009; Cheng & Chan, 2005). In addition, caregivers reported that the emotional support, backup, and reassurance given by the family intervention therapists had a positive impact on reducing their perceived burden (Chan et al., 2009; Budd & Hugher, 1997). According to the studies conducted in Hong Kong, it was found that family psychoeducation for caregivers of schizophrenia had significant effects on their self-efficiency, satisfaction and self-perceived burden of care (Cheng & Chan, 2005; Chien & Wong, 2007; Chan et al., 2009). Community-based family care and developing family support groups were therefore suggested for the caregivers in order to reduce their burden.

Emergency service including hotlines and emergency housing were found to be important for the caregivers in Hong Kong in this study. In Hong Kong, more than 80% of individuals with schizophrenia lived with their family members and about 70% of people with mental illness depend on the assistance and continued involvement of their family (Yip, 2004; Chan, 1991). Caregivers had to take care for the daily living of their relatives and they were the one to provide emotional and psychological support for them. Also, they had to face the risk of violence or suicide by the patients during their mental relapse. Unfortunately, many families expressed not having the knowledge and skills essential to take care of their family members with mental illness (Chan et al., 2009; Yeh et al., 2008). Caregivers in Hong Kong also reflected it was difficult for them to deal with the excessive and uncontrollable emotions and behaviors of the clients (Wong, 2000). This was consistent with the findings of the present study as the need of increasing knowledge of mental illness was perceived to be very important for the caregivers. In addition, high-density living environment among the families with lower socio-economic status in Hong Kong may induce more family conflicts and disharmony in caregiving (Chien et al, 2007). All of the above particular circumstances in Hong Kong explained why emergency services were perceived important among the caregivers in present study.

A positive and significant correlation was found in the item on hotlines service among its importance and satisfaction. The mean of its importance and satisfaction were 3.78 and 3.62 respectively. This reflected that the caregivers were satisfied with the services they had received. Although the caregivers in this study found the emergency service was important, the number of respondent who had received this kind of service was low (N=8) and there was even no respondent had ever received the service of emergency housing. In Western country, the satisfaction level with emergency services was also generally low among caregivers (Morgan, 1989). Therefore, the provision of hotline services, emergency housing and other support service such as respite care should therefore be reinforced.

The results of this study found that “Others” service was perceived to be the least important among the rehabilitation services. The importance of items of “Qi-gong”, “religious activity” and “yoga” were rated below three. This finding was in line with the work of Chien (2003) which found that enhancing leisure and recreational activities was one of the least importance needs of the families in schizophrenia. The reason for this may be that they are not aware of the therapeutic values of these activities. In addition, caregivers devoting most of their time in taking care of their relatives with schizophrenia. The consequences of caregiving include feeling of loss, constraints in social activities, reduced in social life and negative effect of family life were reported in previous studies (Cleary et al., 2006; Magliano et al., 2005). Caregivers may loss interest in leisure activities and neglect its importance due to the burden of caregiving.

5.4.4 LIMITATIONS

Although interesting findings are yielded, this study has a number of limitations that care has to be taken in understanding the results. First of all, there are a number of factors that limit valid generalization of the results to the population. For instance, the samples size was not large enough to conduct a comprehensive investigation on the perceived needs of caregivers of people with schizophrenia in Hong Kong. The participants in this study were recruited by convenience sampling, most of them were drawn from only one geographical region in Hong Kong. The participants were mainly volunteers and most of them were aged 46 or above and attained primary or secondary educational level. The perceived needs of the young or more educated caregivers were not accurately detected in this study. Some of the previous studies found that age and educational level may related to the perception of the perceived need of the caregivers, although no consistent findings were demonstrated (Magliano et al., 2000; Ran et al., 2003; Perlick et al., 2006, Chien et al., 2007; Fan & Chen, 2011). In addition, the participants recruited were caregivers of those clients with good treatment adherence or who received certain kinds of rehabilitation services in the community. The caregivers of those clients who demonstrated extremely poor mental function and treatment compliance were not included for this study. All of the above posed threat to the generalization of findings of the current study.

The second limitation is that only one caregiver was recruited from each family. There may be variations in levels of perceived needs among different family caregivers because of their different family roles, kinship to their relatives, and perceptions of caregiving. Such subtle differences in the perceived needs of caregivers playing different role could not detected in the present study.

The third limitation is that bivariate or multivariate data analysis of the relationship between the perceived rehabilitation needs and socio-demographic characteristics of the respondents was not further conducted.

The forth limitation is that the results of study did not clearly reveal to what extent problems with unmet needs of caregivers was a consequence of lack of services, unawareness of service or unwillingness to use services

5.4.5 IMPLICATIONS TO RESEARCH, PUBLIC POLICY AND CLINICAL PRACTICE

Current medical policy has been focusing on the provision of short-term hospitalization. Most of the clients are discharged home after their hospital care. Under this service model, family members are the main supporters of this system and bear the main responsibilities for patient care in the community. Their burden and distress associated with caring the clients in the community are understandingly high (Winefield & Harvey, 1993; Barrowclough et al., 1996). Assessing their perceived needs would allow systematic identification of specific services and interventions they required. Studies reported that if the perceived needs of caregivers are met, it may prevent them from physical and emotional burnout, and may result in improvements in quality of life (Lauber et al, 2003; Hansson et al., 2003; Slade et al, 2004). Reducing caregivers' burden not only improves their well-being but may also have positive impact on the recovery of the clients (Cleary et al., 2006). This study has investigated the perceived needs of caregivers of people with schizophrenia in Hong Kong. Need assessment is in fact the fundamental way to guiding the government and psychiatric organizations to provide appropriate and client-centered healthcare services and facilities (Asadi-Lari & Gray, 2005). According to the importance placed on needs-led services (Evans, Greenhalgh, & Connelly, 2000), systematic investigation that obtain updated information concerning the rehabilitation needs of caregivers of people with schizophrenia are of upmost importance in the process of rehabilitation policy formulation. Although the current study has limitations that limit some of its power of generalization, the findings we obtained are of direct relevance to inform the government in formulating relevant policies to meet the needs of caregivers. The followings are recommendations based on the findings of this study that the government may consider when reviewing or re-formulating policies pertaining to psychiatric rehabilitation.

5.4.5.1 RECOMMENDATION FOR PUBLIC POLICY DEVELOPMENT

The current criticisms in the society pointed out that the government does not allocate enough resources or have evidence-based policies to address the needs of people with mental illnesses and their caregivers. This study provides evidence for the government to review and revise their policies so that resources can be allocated efficiently to meet their real needs. If this can be implemented, their quality of life will be enhanced. As a result, tragedies such as violence or suicides resulting from this population may be reduced. The findings of this study have identified and prioritized the rehabilitation needs of caregivers of people with schizophrenia. At the needs level, “Stress management”, “Knowledge on illness, caring skills, and relationship” and “Societal and financial support” were perceived as the most important rehabilitation needs by the respondents. At the service level, “Family rehabilitation” and “Emergency service” were regarded as the most important services towards the caregivers. However, very few of them have actually received these services. This suggested that the availability and accessibility of these services are extremely limited. The first recommendation we make is to allocate more resources in terms of funding and manpower on the provision of rehabilitation services for caregivers. As to the priority on the development of services, it is suggested that the social, welfare and financial support for the caregivers should first be strengthened. As caregivers expressed economic hardship, government should provide financial assistance to relieve their financial burden for the purchase of new medication and other important expenses. Use of atypical drugs is essential as caregivers expressed the need in reducing the burden brought by the side effects of the old medication. The new medications are more effective in symptom management and with lesser side-effects, therefore it could help to ease the burden of the caregivers (Tsang et al., 2003; Chien & Norman, 2003).

Caregivers demonstrated high level of need in receiving support given by mental health professionals such as psychologist, occupational therapist, etc.. However, unfortunately these kinds of professional contacts are very limited. Another recommendation for the government is therefore to mobilize resources to increase manpower of the mental health professionals to improve the availability and accessibility of rehabilitation services for the caregivers in the community. Traditionally, emphasis has only been given to the training of psychiatrists and nurses. The results suggested that allied health professionals such as occupational therapists, social workers, psychologists are of more urgent needs to provide services perceived to be important by our respondents. Resulting from this recommendation, the government may consider investing more resources in the training of mental health professionals at tertiary educational settings to increase the number of admissions and employing more professors for this purpose.

In this study, caregivers expressed the needs in increasing channel for seeking help and increasing their awareness of the available support in the community. Caregivers expressed that mental health services were not easily accessible to the public and did not know where to seek advices from mental health professionals (Tsang et al., 2003). Based on this need of the caregivers, resources should be shifted from hospitals to the community. As most of the respondents and their family members with mental illness reside in the community, more community based centers should be set up with the primary purpose of providing support for the caregivers. The community based family center can provide immediate and tailor-made social support to alleviate caregivers' emotional crisis in caregiving. Overseas experiences suggest that caregivers may also be beneficial from the mutual support organised by the family centres (Heller et al., 1997; Norton, Wandersman & Goldman, 1993). Mutual support groups may be provided in these centres for caregivers to acquire knowledge and skills on caregiving, building up harmonious family life, and encouraging professionals as collaborator (Chien & Chan, 2005; Chan, 2011). Caregivers can get the most updated resources or information for caregiving and they can also seek emergency advice in case of crisis management such as mental relapse or risk of violence of their relatives with schizophrenia (Cook, Heller & Pickett-Schenk, 1999; Chien, Chan & Thompson, 2006; Chatterjee et al., 2011.)

The current study revealed that caregivers showed concern about the public discrimination towards mental illness. Unfortunately, anti-stigma campaigns and educational programs were severely inadequate. It is now clear that the impact of the stigma of having a family member with mental illness is pervasive and strong (Chang & Horrocks, 2006). In Hong Kong, caregivers in general feel shameful and guilt to talk about the mental illness with their relatives and friends (Tsang et al., 2003; Tseng, Lu & Yin, 1995; Chang & Horrocks, 2006). As a result, caregivers tended to conceal they had a family member with mental illness because they afraid of being ridiculed and discriminated by the others. This highlighted the importance of formulating policies and strategies to reduce social stigma on people with mental illness and their family caregivers. Anti-stigma campaigns should be organized by policy makers, administrators and healthcare professionals to promote the welfare and thus quality of life of those with mental illness. Previous studies have provided support for such campaigns (Lam et al., 2010; Tsang et al., 2003; Tsang et al., 2003; Pearson & Tsang, 2004). Policy makers and service providers are suggested to facilitate the reintegration of those with mental illness they are capable of assuming meaningful roles in the community and they deserve equal respect with other citizens. Furthermore, public education programs could be strengthened by providing information on positive treatment outcomes, prevalence rates of violent behaviors among people with mental illness and public misconceptions (Lam et al., 2010; Tsang et al., 2003;).

5.4.5.2 RECOMMENDATIONS FOR CLINICAL PRACTICE

This study has provided solid evidence in Hong Kong that we should provide family intervention to improve the current care for the caregivers as studies suggested that people can participate in their own care better if their knowledge deficits are removed (Mericle, 1999). Previous studies demonstrated that some family intervention strategies such as psychoeducation and support groups had a positive impact on the caregivers and thus the recovery of individual with mental illness (Alicia et al., 2012; Chien & Wong, 2007). Psychoeducation is the strategy to engage, inform and educate family members about mental disorders, their treatments, personal coping techniques, and available resources (Chan et al., 2009). The caregivers not only benefit from the knowledge or skill-training component of psychoeducaion, they also reported that emotional support and reassurance provided by therapists were very helpful (Budd & Hughes, 1997). The finding in this study showed that caregivers need support given by mental health professionals. As a result, therapeutic alliance was valuable for the caregivers. Given the importance of these services, clinicians are suggested to organize more psychoeducation program or the caregivers.

The finding in this study indicated that "Stress management" was perceived to be importance for the caregivers. Caregivers face different kinds of burden such as physical, psychological and financial in caregiving from day to day. The present study found that caregivers were very stressful over patients' future and safety, had psychological burden due to the lack of understanding of the patient's condition, and this finding was in line with previous studies (Pearson & Tsang, 2004; Tsang et al, in press). It is difficult for them to find the way to relieve their burden. Therefore, more psychosocial interventions and counseling services are suggested for the caregivers to prevent their emotional burnout (Lam et al, 2010; Chang & Horrocks, 2006; Hou et al., 2008).

Finally, the findings of this study also reflected that caregivers perceived emergency services were important. Clinicians may be advised to strengthen the emergency service such as twenty-four hours hotlines services and emergency outreaching psychiatric team. The community outreach team developed in multidisciplinary approach including medical, psychological, occupational therapist, and social work professionals is suggested to assist and support caregivers in case of emergency.

5.4.5.3 IMPLICATION FOR FURTHER STUDY

Although we have generated meaningful findings and relevant policy and practice recommendations listed above, the current study has many limitations that pose threat to the external validity. Further studies are needed to address the methodological problems.

Further studies are recommended to recruit a larger sample size of caregivers from different regions in Hong Kong in order to increase the generalizability to the whole population. Also, caregivers with different socio-demographic background should be recruited so as to investigate the difference on the perceived need among caregivers of different age groups, educational level and employment status etc. In addition, further studies are needed to explore the impact of different family roles, kinship to the client and the perceptions of caregiving in relation the perceived needs should be conducted. Further studies should try to recruit those caregivers who seldom or never exposed to the rehabilitation services with collaboration with community family centers or social welfare department. Last but not least, a longitudinal study is suggested for further exploration on the causal relationship between the socio-demographic factors of the caregivers and their perceived needs.

Implications of the current study go beyond mental illness in Hong Kong. Future studies to explore rehabilitation needs for other clinical conditions that caregivers similarly experience much burden could simply be conducted by using similar methodology of the present study to develop relevant questionnaires. For instances, caregivers of those with dementia and stroke may easily benefit from the current study.

More importantly, the current study has demonstrated the method that the rehabilitation needs of caregivers of 16 million of individuals with severe mental illness in the mainland may be identified so that relevant policy may be formulated. The questionnaire (PRNQ-C) that we developed has great potential to be used in some modernized and westernized cities such as Beijing, Shanghai and Wuxi because these cities have developed a similar mental health system and possessed medical technologies which are comparable to Hong Kong. Further amendment and validation are suggested to investigate this possibility. Using similar methodology and the adjustment of questionnaires, importance and satisfaction of perceived needs of caregivers of other types of psychiatric conditions (e.g., Depression, dementia, or substance abuse, etc.) may also be assessed.

CHAPTER 6: CONCLUSION

The PRNQ-C was initially validated and used as the assessment tool to investigate the perceived needs of caregivers of people with schizophrenia. The findings have deepened our understanding in the perceived needs from the perspective of the caregivers. Knowledge on mental illness, stress management, and societal and financial support were the most importance perceived needs of the caregivers. On the other hand, family intervention and emergency services were the most important rehabilitation services indicated by the caregivers. Perceived needs were closely related to some demographic variables such as living condition and employment status. Finally, correlation between perceived importance and satisfaction of needs was found in some items. Based on the results collected in this study, we have provided the following recommendations in policy development and clinical practice to policy makers and rehabilitation practitioners in Hong Kong. They are in descending order of priority:

Public policy development:

- Allocate more resources in terms of funding and manpower on the provision of rehabilitation services

- Mobilize resource to increase manpower of mental health professionals such as occupational therapist, social worker and psychologist by means of invest more resource in the training of mental health professionals at tertiary educational setting
- Enhance community based services by establishing community-based family centres for caregiver supports and information services.
- Provide financial support on the new medication and other important expense for people with schizophrenia and their families
- Promote anti-stigma campaigns and education programs to reduce social discrimination and increase the acceptance of people with mental illness by the public

Clinical practice:

- Provide more family intervention programs such as psychoeducation to support and give practical advices for caregivers on psychiatric symptoms, use of medications, and management of disturbing behaviour and disabilities.
- Provide adequate counselling services to alleviate caregivers' stress and burden in taking care of their relatives with schizophrenia.

- Strengthen the emergency service such as twenty-four hours hotline services and emergency outreaching psychiatric team for immediate support for the caregivers.

This is the beginning of the process of evidenced-based policy development. In a long run, we should implement periodic large scale rehabilitation needs study in Hong Kong to obtain updated information concerning the needs of caregivers of people with schizophrenia, to examine any changes throughout the course of illness. Upon further validations, the PRNQ-C may be applied in other Chinese societies such as Taiwan and the mainland China. Using the same research methodology, similar studies to assess caregivers' needs in other groups of psychiatric disabilities such as depression and dementia can be conducted.

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Appendix 1a Consent Form (English Version)

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

Research Project Informed Consent Form

Project title: Rehabilitation Needs of People with Schizophrenia and their Caregivers in Hong Kong: Implication for Public Policy

Principal Investigator

Dr. Hector Tsang, Associate Professor of the Department of Rehabilitation Sciences at The Hong Kong Polytechnic University

Project information:

The aim of this study is to identify rehabilitation needs of people with schizophrenia and their caregivers in Hong Kong. The results of the study could provide information and direction for formulation of public policy and provision of mental health services which can help the government and service providers better allocate and prioritize resources based on the needs of clients and caregivers, and provide better quality of services to fit their aggregated needs. The study will involve participating in a focus group interview which will take you about one and half hour.

The interview should not result in any undue discomfort, but you will need to be audio-taped in the focus group interview. All information related to you will remain confidential, and will be identifiable by codes known only to the researcher.

Thank you for your interest in participating in this study.

Consent:

I, ____________________________, have been explained the details of this study. I voluntarily consent to participate in this study. I understand that I can withdraw from this study at any time without giving reasons, and my withdrawal will not lead to any punishment or prejudice against me. I am aware of any potential risk in joining this study. I also understand that my personal information will not be disclosed to people who are not related to this study and my name or photograph will not appear on any publications resulted from this study.

I can contact the chief investigator, Dr Hector Tsang at telephone 27666750 for any questions about this study. If I have complaints related to the investigator(s), I can contact Mrs Michelle Leung, secretary of Departmental Research Committee, at 27665397. I know I will be given a signed copy of this consent form.

Signature (subject): ____________ Date: ____________________

Signature (witness):____________ Date______________________:

Appendix 1b   Consent Form (Chinese Version)

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

香港理工大學康復治療科學系科研同意書

科研題目：香港精神分裂症患者及照顧者的復康需要調查：對設立公共政策的應用

科研負責人：

香港理工大學康復治療科學系副教授曾永康博士

科研內容：

此項研究的目的是辨認香港精神分裂症患者及其照顧者的復康需要。本調查所得的結果能協助公共政策的制定及精神健康服務的提供，並協助政府及自願機構藉著服務使用者的需要更妥善地安排資源及提高服務質素。本調查中所涉及的聚焦小組需要花閣下約一個半小時/問卷調查需要花費閣下約半小時。

這項調查不會引起任何不適的感覺，但閣下需要做以下所要求的事項（如：錄音）。 凡有關閣下的資料均會保密，一切資料的編碼只有研究人員知道 。

謝謝閣下有興趣參與這項研究 。

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

同意書：

本人______________已瞭解此次研究的具體情況。本人願意參加此次研究，本人有權在任何時候、無任何原因放棄參與此次研究，而此舉不會導致我受到任何懲罰或不公平對待。本人明白參加此研究課題的潛在危險性；本人的資料將不會洩露給與此研究無關的人員；我的名字或相片不會出現在任何出版物上。

本人可以就此項研究相關的任何問題，用電話 27666750 來聯繫此次研究課題負責人，曾永康博士。若本人對此研究人員有任何投訴，可以聯繫梁女士（部門科研委員會秘書），電話：27665397。本人亦明白，參與此研究課題需要本人簽署一份同意書。

簽名（參與者）：________________ 日期：____________________

簽名（證人）：______________ 日期：____________________

Appendix 2a. Perceived Rehabilitation Needs Questionnaire (Caregiver) – [PRNQ – C]

Questionnaire on the Rehabilitation Needs of Caregivers of People with Schizophrenia in Hong Kong

Introduction

This questionnaire aims at identifying the rehabilitation needs of caregivers of people with schizophrenia in Hong Kong. The research findings will help in the formulation of public policies in Hong Kong and in the provision of mental health services in the future. The findings will also help the government and voluntary organizations allocate resources more appropriately according to the needs of service users and enhance the quality of service.

There are 3 parts in the questionnaire. Part I assesses **the importance of each type of rehabilitation need to you and your satisfaction** towards it. Part II assesses **the importance of each type of rehabilitation service at present and your level of satisfaction** towards it. Part III is about your background information for data analysis.

Part I: Rehabilitation Needs

There are a total of 12 types and 50 items of rehabilitation needs of caregivers of schizophrenia patients. Please rate the importance of each rehabilitation need. Please rate the importance of each item using the scale 1 to 5 with 1 being not very important and 5 being very important. Hence, please assess the sufficiency of the current provision of that particular service. Please rate the sufficiency using the scale 1 to 5 with 1 being not very sufficient and 5 being very sufficient.

A. Workplace/ Employment	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
1. Reduce the influence on one's work performance because of the phone calls made by the patient	**1**	**2**	**3**	**4**	**5**	**NA**						
2. Reduce discrimination against family members of mental illness patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
3. Able to handle one's work and take care of the patient at the same time	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

B. Housing	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
4. Reduce the waiting time for halfway house	**1**	**2**	**3**	**4**	**5**	**NA**						
5. Increase living space	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

C. Community Support and Welfare System	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
6. Increase channels of seeking help	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

7. Provide psychological counseling service	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
8. Provide support catered for the needs of caregivers	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
9. Provide information on identifying the kind of support required	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
10. Increase the awareness of support	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

D. Medical Needs	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
11. Reduce the burden of urging patient to take medication	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
12. Reduce the worries on the patient's taking of medication	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
13. Reduce the burden brought by the side-effect of medication of the patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
14. Increase support by other mental health professionals apart from doctors	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

E. Financial Needs	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
15. Reduce financial reserve for the patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
16. Increase the right of managing the Comprehensive Social Security Assistance (CSSA) allowance of the patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

17. Provide sufficient money for the expenses of new medication	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

F. Social Life	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←----------→ Satisfactory				
18. Increase time for social life	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
19. Reduce self-isolation and social withdrawal	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
20. Expand the circle of friends in which one is the centre of the circle	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
21. Increase support and understanding from friends and thus expand one's social network	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

G. Family	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←----------→ Satisfactory				
22. Improve relation with other family members	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
23. Increase the acceptance of the patient by the family	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
24. Reduce the influence on the relation between caregivers and patient resulted from urging the patient to take medication	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
25. Enhance communication skills with the patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
26. Accept some of the behaviors of the patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

27. Strengthen communication with the patient and build a mutual trust relation	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
28. Provide knowledge on differentiating the patient's personalities from the symptoms	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
29. Change the conception that the caregiver is responsible for the illness of the patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

H. Awareness of the Illness	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
30. Increase caregiver's knowledge of mental illnesses	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
31. Be available to certified health or rehabilitation professionals (e.g., psychologist, occupational therapist, etc.) on answering enquiries	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
32. Increase channels of obtaining information	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

I. Discrimination	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
33. Reduce discrimination by the society	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
34. Reduce self-discrimination	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
35. Reduce the deprivation for being family member of mental illness patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

J. Stress Management	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
36. Reduce the apprehension of the change of condition of the patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
37. Reduce the pressure on working and taking care of the patient at the same time	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
38. Reduce the worries over unexpected problem of the patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
39. Reduce the psychological burden due to the lack of understanding of the patient’s condition	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
40. Reduce the frustration brought by the fluctuation of the patient’s condition	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
41. Obtain peer support and encouragement	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
42. Reduce the worries over the patient’s future	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
43. Reduce the worries over the patient’s safety	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

K. Self-care	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
44. Make time to take care of the patient’s daily life	**1**	**2**	**3**	**4**	**5**	**NA**						
45. Strengthen caring skills	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
46. Understand the proper attitude of care taking	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
47. Reduce the difficulty in care taking brought by the daily habit of the patient	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

L. Entertainment	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
48. Increase the time for leisure activities	**1**	**2**	**3**	**4**	**5**	**NA**						
49. Increase the type of leisure activities	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
50. Increase the motivation of participating in leisure activities	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

Apart from the above, do you have any other opinions towards the rehabilitation needs?

--- Part I ---

Part II: Rehabilitation Service

There are a total of 7 types and 13 items of rehabilitation service for mental illness patients. Please rate **the importance of each rehabilitation service to you** using the scale 1 to 5 with 1 being not very important and 5 being very important. Hence, please answer if you have used the service before. If yes, please rate **your level of satisfaction towards the service** using the scale 1 to 5 with 1 being not satisfactory and 5 being very satisfactory. You are not required to answer the part on your level of satisfaction if you have not used the service before.

A. Family rehabilitation	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
1. Family Therapy*	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

B. Psychotherapy	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
2. Psychological Therapy*	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

C. Self-management	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
3. Self-management education and training*	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

D. Social activity	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
4. Self-help organization	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
5. Day training and activity centre	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

E. Social Welfare	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
6. CSSA Allowance	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
7. Compassionate Housing	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

F. Emergency Services	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
8. Hotlines (e.g. suicide and family violence)	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
9. Emergency housing	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

G. Others	Importance					Have you used this service before? (if yes,) →		Satisfaction				
	Not Very Important ←-----→ Very Important							Not Satisfactory←-----------→ Satisfactory				
10. Qi-gong	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
11. Activity on the prevention of discrimination	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
12. Religious activity	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**
13. Yoga	**1**	**2**	**3**	**4**	**5**	**Yes**	**No**	**1**	**2**	**3**	**4**	**5**

Apart from the above, do you have any other opinions towards each type of rehabilitation service?

--- Part II ---

Part III: Background Information

The following questions are about your background information. This information will allow us to place you in the group of people with similar background in our data analysis.

Sex: ☐ Male ☐ Female
Age: ☐ 18 – 25 Years ☐ 26 – 35 Years ☐ 36 – 45 Years ☐ 46 – 55 Years ☐ 56 Years or above
Education: ☐ Uneducated ☐ Primary educated ☐ Secondary educated ☐ Tertiary educated or above ☐ Others, please specify:___________
Marital Status: ☐ Single ☐ Married ☐ Divorced ☐ Widowed
Living with family member with schizophrenia: ☐ Yes ☐ No
Employment Status: ☐ Open employment, please specify:☐ Administrative ☐ Professional ☐ Clerk ☐ Service Industry ☐ Salesperson
☐ Technical ☐ Non-technical ☐ Others, please specify:_________
If currently under employment, your monthly salary is: ☐ $5,000 or below ☐ $5,001 – $7,000 ☐ $7,001 - $10,000 ☐ $10,001 – 15,000
☐ $15,000 or above
If currently unemployed, you source of income is: ☐ Savings ☐ Family ☐ Disability Allowance ☐ CSSA Allowance
☐ Others, please specify____________________
Years of taking care of family member with schizophrenia: ☐ 2 years or below ☐ 2 – 5years ☐ 5 – 10 years ☐ 10 years or above

-- End of Questionnaire, thank you! --

Glossary for the Services provided in Hong Kong regarding
Public Policy Research (PPR)
by

(Principal Investigator: Dr. Hector W.H. Tsang, Department of RS, The Hong Kong Polytechnic University)

Supported Employment

Supported employment aims at helping disabled persons with difficulties in obtaining employment by providing them with opportunities of **open employment** and supported services, as well as in-service follow up and counseling. Services include selecting employment, arranging interview with employers and accompanying the service user to job interview. After the successful recommendation of a job, the service provider will pay regular visits and liaise with the employer, service user, his/her family and the referral agency to provide in-service follow up service.

Social Enterprises

Majority of these social enterprises are created by non-profit making/ non-governmental organizations. Social enterprises are operated by business principles and aims at making profit to contribute to the society. The profit made will be used in helping the vulnerable, in promoting community development and in the investment of the social enterprise itself. Social enterprise emphasizes more on its community value instead of making the greatest profit.

Community Outreach Mental Rehabilitation Service

An outreach mental rehabilitation service provided by professionals (e.g. psychiatrist, nurse, occupational therapist, social worker, etc.) which mostly takes place in the household of the service users or in the community.

Family Therapy

Targeted at the family and using the family as a unit, family therapy is a type of group therapy using modes like verbal therapy and interaction. It aims at reducing the physical and psychological symptoms of individuals brought by the family, solving disputes among family members and reconstruct.

Psychological Therapy

Psychological therapy is provided by clinical psychologists. Using psychology principles, clinical psychologists help clients to solve problems in one’s emotion, ideology and behaviour, e.g. apprehension, fear, depression, difficulty in getting along with others, etc. The aim of psychological therapy is to promote one’s mental and physical well-being and improve one’s ability of adapting to life.

Self-management Education and Training

Generally speaking, it includes all education and training which promotes one’s mental health which aims at enhancing one’s ability to live independently, avoiding recurrence and improving one’s quality of life (e.g. healthy living style, medication management, stress management, building up of insight, etc.).

Clubhouse

In the clubhouse, rehabilitated patients can work voluntarily as life-long members and work side by side with other staff. It allows members to choose the job they like and their choices will be respected. Apart from developing their skills at work, working in the clubhouse also allows members to make the best use of their strengths. The recognition and respect of their ability explains why members are eager to go to the clubhouse everyday.

Cognitive remediation Therapy (CRT)

CRT uses multi-media computer programmes which comprise audio and animation elements and it aims at training the cognitive ability of the brain of mental illness patients step by step. It includes cognitive training on concentration, memorization, computation, problem solving, etc. This training enables the mental illness patients aware of their defects, and thus enhancing their daily function.

Assertive Community Treatment (ACT)

Assertive Community Treatment is a way of providing services. It aims at providing a flexible and comprehensive service to patients with multiple and complex needs. There are several major components in ACT which accounts for its difference with other ways of case management. These components include lower staff-consumer ratio, team care, consumer-oriented service, assertive outreach and extended service, etc.

Appendix 2b. Perceived Rehabilitation Needs Questionnaire (Caregiver) – [PRNQ – C]

香港精神病患者照顧者康復需要問卷調查

簡介

此問卷旨在辨認香港精神分裂症患者照顧者的康復需要。調查所得的結果將協助制定香港公共政策及日後提供精神健康服務，並協助政府及志願機構根據服務使用者的需要，更妥善地安排資源及提高服務質素。

本問卷分為三部份。第一部份將以**各康復需要對您本人的重要性**及**您本人對各康復需要的滿足程度**進行評分。第二部份將以現有**各項康復服務對您本人的重要性及滿意程度**進行評分。第三部份將問及您的背景資料，以便進行資料分析。

第一部份：康復需要

我們將列舉出一共12類51項精神病患者照顧者的康復需要。請為以下**各項康復需要對您本人的重要性**評分，以1至5分為標準，請圈出**各需要對您本人的重要性**，1分代表非常不重要，5分代表非常重要。然後就該需要，再以1至5分為標準，圈出**各服務對您本人各項需要的滿足程度**，1分代表未能滿足，5分代表十分滿足。

A. 工作 / 就業	重要性					曾否接受有關服務？(如回答是) →		滿意程度				
	非常不重要 ←-----------→ 非常重要							未能滿意 ←-----------→ 十分滿意				
1. 減少因患者致電而影響工作表現	**1**	**2**	**3**	**4**	**5**	**不 適 用**						
2. 減少因家人是精神病患者而遭受的歧視	**1**	**2**	**3**	**4**	**5**	**是**	**否**	**1**	**2**	**3**	**4**	**5**
3. 能夠同時兼顧工作及照顧患者	**1**	**2**	**3**	**4**	**5**	**是**	**否**	**1**	**2**	**3**	**4**	**5**

B. 住宿	重要性					曾否接受有關服務？(如回答是) →		滿意程度				
	非常不重要 ←-----------→ 非常重要							未能滿意 ←-----------→ 十分滿意				
4. 縮短中途宿舍輪候時間	**1**	**2**	**3**	**4**	**5**	**不 適 用**						
5. 增加居住空間	**1**	**2**	**3**	**4**	**5**	**是**	**否**	**1**	**2**	**3**	**4**	**5**

C. 社區支援及福利配套	重要性					曾否接受有關服務？(如回答是) →		滿意程度				
	非常不重要 ←-----------→ 非常重要							未能滿意 ←-----------→ 十分滿意				
6. 增加求助渠道	**1**	**2**	**3**	**4**	**5**	**是**	**否**	**1**	**2**	**3**	**4**	**5**
7. 提供心理輔導	**1**	**2**	**3**	**4**	**5**	**是**	**否**	**1**	**2**	**3**	**4**	**5**

8. 提供專注於照顧者需求的支援	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
9. 提供知識判定需要何種支援	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
10. 增加對支援的認知	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

D. 醫療	重要性					曾否接受有關服務？(如回答是)		滿意程度				
	非常不重要 ←------------→ 非常重要							未能滿意 ←------------→ 十分滿意				
11. 減輕勸患者服藥的負擔	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
12. 減少對患者有否依指示服藥的擔心	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
13. 減輕因患者受藥物副作用困擾而加重的負擔	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
14. 增加醫生以外的其他精神科專業人仕的支援	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

E. 財政	重要性					曾否接受有關服務？(如回答是)		滿意程度				
	非常不重要 ←------------→ 非常重要							未能滿意 ←------------→ 十分滿意				
15. 減少額外預備金錢予患者	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
16. 增加權利管理患者綜援	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
17. 提供足夠費用應付新藥開支	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

F. 社交	重要性					曾否接受有關服務？(如回答是)		滿意程度				
	非常不重要 ←------------→ 非常重要					→		未能滿意 ←------------→ 十分滿意				
18. 增加社交時間	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
19. 減少自我封鎖及社交退縮	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
20. 擴大以自己為中心的朋友圈	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
21. 增加朋友支持及諒解從而擴展社交圈子	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

G . 家庭	重要性					曾否接受有關服務？(如回答是)		滿意程度				
	非常不重要 ←------------→ 非常重要					→		未能滿意 ←------------→ 十分滿意				
22. 改善與其他家人的關係	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
23. 增加家人對患者的接納	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
24. 減少因常催促患者服藥對彼此關係的影響	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
25. 增強與患者的溝通技巧	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
26. 增加對精神病的認識，從而接納患者的部份行為	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
27. 加強與患者的溝通，建立互信關係	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
28. 提供知識判斷何謂患	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

者本身性格, 何謂病徵											
29. 改變被其他家人認定要為患者的病負責	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

H. 對病情的認知	重要性					曾否接受有關服務？(如回答是) →		滿意程度				
	非常不重要 ←-----------→ 非常重要							未能滿意 ←-----------→ 十分滿意				
30. 增加對精神病的認識	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
31. 提供專業人仕解答疑難	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
32. 增加獲得資訊的渠道	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

I. 歧視	重要性					曾否接受有關服務？(如回答是) →		滿意程度				
	非常不重要 ←-----------→ 非常重要							未能滿意 ←-----------→ 十分滿意				
33. 減少遭社會歧視	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
34. 減少自我歧視	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
35. 減少因家屬患精神病而遭到剝削	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

J. 壓力管理	重要性					曾否接受有關服務？(如回答是) →		滿意程度				
	非常不重要 ←-----------→ 非常重要							未能滿意 ←-----------→ 十分滿意				
36. 減少對患者病情發展的焦慮	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
37. 減輕兼顧工作與照顧患者的壓力	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
38. 減少對患者突發問題的擔憂	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

39. 減少因對病情缺乏認識形成心理負擔	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
40. 減少因患者的病情反覆而沮喪	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
41. 獲得同伴支持及鼓勵	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
42. 減少對患者將來的憂慮	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
43. 減少對患者安全的憂慮	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

K. 自我照顧	重要性					曾否接受有關服務？(如回答是) →		滿意程度				
	非常不重要 ←------------→ 非常重要							未能滿意 ←------------→ 十分滿意				
44. 騰出時間兼顧患者日常起居生活	**1**	**2**	**3**	**4**	**5**	**不適用**						
45. 加強照顧技巧	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
46. 明白正確的照顧態度	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
47. 減低因患者生活習慣而造成的照顧困難	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

L. 娛樂	重要性					曾否接受有關服務？(如回答是) →		滿意程度				
	非常不重要 ←------------→ 非常重要							未能滿意 ←------------→ 十分滿意				
48. 增加娛樂時間	**1**	**2**	**3**	**4**	**5**	**不適用**						
49. 增加娛樂種類	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
50. 增加娛樂動力	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

--- 第一部份完 ---

第二部份：康復服務

我們將列舉出一共 7 類 13 項精神病患者照顧者的康復服務。請就以下**各康復服務對您本人的重要性**進行評分，以 1 至 5 分為標準，請圈出**您本人對各需要的重要性**，1 分代表非常不重要，5 分代表非常重要。然後請填寫**您本人曾否接受該項服務**，如曾接受該項服務，請再以 1 至 5 分為標準，圈出**您本人對各服務的滿意程度**，1 分代表未能滿意，5 分代表十分滿意。如未曾接受該項服務，則無需填寫對該服務的滿意程度。

A. 家庭康復	重要性					曾否接受此服務？		滿意程度				
	非常不重要 ←------------→ 非常重要					(如回答是) ——→		未能滿意 ←------------→ 十分滿意				
1. 家庭治療*	**1**	**2**	**3**	**4**	**5**	**是**	否	**1**	**2**	**3**	**4**	**5**

B. 心理治療	重要性					曾否接受此服務？		滿意程度				
	非常不重要 ←------------→ 非常重要					(如回答是) ——→		未能滿意 ←------------→ 十分滿意				
2. 心理治療*	**1**	**2**	**3**	**4**	**5**	**是**	否	**1**	**2**	**3**	**4**	**5**

C. 自我管理	重要性					曾否接受此服務？		滿意程度				
	非常不重要 ←------------→ 非常重要					(如回答是) ——→		未能滿意 ←------------→ 十分滿意				
3. 自我管理教育及訓練*	**1**	**2**	**3**	**4**	**5**	**是**	否	**1**	**2**	**3**	**4**	**5**

D. 社交生活	重要性					曾否接受此服務？		滿意程度				
	非常不重要 ←------------→ 非常重要					(如回答是) ——→		未能滿意 ←------------→ 十分滿意				
4. 自助組織	**1**	**2**	**3**	**4**	**5**	**是**	否	**1**	**2**	**3**	**4**	**5**
5. 活動及訓練中心	**1**	**2**	**3**	**4**	**5**	**是**	否	**1**	**2**	**3**	**4**	**5**

E. 社區福利保障	重要性					曾否接受此服務？		滿意程度				
	非常不重要 ←------------→ 非常重要					(如回答是) ————→		未能滿意 ←------------→ 十分滿意				
6. 綜援	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
7. 恩恤住屋	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

F. 緊急服務	重要性					曾否接受此服務？		滿意程度				
	非常不重要 ←------------→ 非常重要					(如回答是) ————→		未能滿意 ←------------→ 十分滿意				
8. 電話熱線 (如自殺或家庭暴力	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
9. 緊急住所服務	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

G. 其他	重要性					曾否接受此服務？		滿意程度				
	非常不重要 ←------------→ 非常重要					(如回答是) ————→		未能滿意 ←------------→ 十分滿意				
10. 氣功	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
11. 預防歧視活動	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
12. 宗教活動	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**
13. 瑜伽	**1**	**2**	**3**	**4**	**5**	是	否	**1**	**2**	**3**	**4**	**5**

除上述以外，請問您對現有各康復服務有沒有其他意見？____

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--- 第二部份完 ---

第三部份：背景資料

以下問題是關於您的背景資料，方便我們在分析研究結果時，將您的資料和其他與您背景相似的人士歸類：

性別： □ 男 □ 女
年齡： □ 18 – 25 歲 □ 26 – 35 歲 □ 36 – 45 歲 □ 46 – 55 歲 □ 56 歲或以上
教育程度：□ 未曾接受正式教育 □ 小學 □ 中學 □ 大學或以上 □ 其他，請註明：____________________
婚姻狀況：□ 單身 □ 已婚 □ 離婚 □ 喪偶
是否與患者同住： □ 是 □ 否
就業狀況： □ 全職工作，請註明：□ 行政人員 □ 專業人員 □ 文職 □ 服務性行業 □ 商店銷售人員 □ 技術工人
□ 非技術工人 □ 其他，請註明：____
如正在就業，月入： □ $5,000 或以下 □ $5,001 – $7,000 □ $7,001 – $10,000 □ $10,001 – $15,000 □ $15,001 或以上
如暫無職業，主要收入來源： □ 自行賺取 □ 儲蓄 □ 家庭 □ 傷殘津貼 □ 綜援 □ 其他，請註明：
自患者發病開始，照顧患者的年期： □ 2 年或以下 □ 2 – 5 年 □ 5 – 10 年 □ 10 年以上

--全問卷完，謝謝！--

Glossary for the Services provided in Hong Kong regarding Public Policy Research (PPR)

by

(Principal Investigator: Dr. Hector W.H. Tsang, Department of RS, The Hong Kong Polytechnic University)

輔助就業

輔助就業服務主要為在就業上有困難的殘疾人士安排**公開就業**機會及提供支援服務，並給予在職跟進及輔導。服務會提供就業選配、與僱主安排面試及陪同服務使用者前往面試。在成功介紹工作後會透過定期探訪及與僱主、服務使用者、其家人及轉介機構聯絡提供在職跟進服務。

社會企業

大多數是由非營利組織/非政府組織實施，社會企業透過商業手法運作，賺取利潤用以貢獻社會。它們所得盈餘用於扶助弱勢社群、促進社區發展及社會企業本身的投資。它們重視社會價值，多於追求最大的企業盈利。

社區外展精神康復服務

由專業人仕(如:精神科醫生, 護士, 職業治療師, 社工等)所提供的外展精神康復服務, 服務或訓練地點一般於服務使用者的家居或在社區進行。

家庭治療

家庭治療是以家人為單位及對象的一種團體治療，經由語言、互動等治療模式，其目的在消除個人因家庭所產生的生理或心理症狀，解決之間的衝突，重新建構

心理治療

由臨床心理學家所提供的心理治療, 臨床心理學家利用心理學的原理去幫助當事人解決各種情緒、思想、行為上的困擾，例如:過份憂慮、恐懼、抑鬱及與人相處困難等等。治療的最終目的是為促進身心健康，增加適應 生活的能力。

自我管理教育及訓練

泛指所有促進自我精神健康的教育及訓練, 從而提高獨立生活能力, 避免病發及改善生活質數.(如: 健康生活, 藥物管理, 壓力管理, 病悉感建立等) 。

會所 (Clubhouse)

會所的運作模式，讓精神病康復者能夠自願地以終身會員的身份參與會所工作，與會所職員並肩管理會所日常運作。會員可自由選擇自己喜歡的工作，會所亦尊重他們的選擇。會員在會所工作，不但可發展其工作技能，並可有機會從實際工作中發揮會員的優點。會員的才華被肯定、被尊重，是令會員每天都期待身處會所的重要元素。

認知矯正治療 Cognitive remediation Therapy (CRT)

CRT是運用語音及動畫等的多媒體電腦程式, 循序漸進地訓練精神病患者的腦部認知功能, 內容包括專注力,記憶力,計算,問題處理能力等基本腦部認知的訓練. 透過這些訓練, 精神病患者能改善認知缺陷, 從而提升日常生活的功能。

積極性社區治療 (Assertive Community treatment, ACT)

積極性社區治療是一種供應服務的模型，目的是為那些同時有多種複雜需要的病人，提供靈活與全面的服務。積極社療有幾個獨特的主要成分，故此與其他個案管理模式不同，這些特點,包括:較低的職員對消費者比率、團隊護理方式、以消費者為本的服務方式、積極性的外展與延續服務等。