PERCEIVED REHABILITATION NEEDS OF PEOPLE WITH SCHIZOPHRENIA AND THEIR CAREGIVERS IN WUXI

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Perceived Rehabilitation Needs of People with Schizophrenia and their Caregivers in Wuxi

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CERTIFICATE OF ORIGINALITY

I hereby declare that the thesis is my own work and that, to the best of my knowledge and belief, it produces no material previously published or written, nor material that has been accepted for the award of any other degree or diploma, except where due acknowledgement has been made in the text.

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Tsui Chi Man

ABSTRACT

This three-phased study aimed to 1) examine the psychometric properties of the two questionnaires developed in Hong Kong, namely, The Perceived Rehabilitation Needs Questionnaire for People with Schizophrenia (PRNQ-S) and The Perceived Rehabilitation Needs Questionnaire for Caregivers of people with schizophrenia (PRNQ-C), for their use in Wuxi, 2) explore and compare the views of the people with schizophrenia and their caregivers towards the needs for psychiatric rehabilitation, and 3) measure and compare their perceived rehabilitation needs using the Wuxi version of the two questionnaires (i.e., PRNQ-S-WX and PRNQ-C-WX). In the first phase, exploratory factor analysis was to explore the interrelationships among the items of both scales based on a sample of 250 persons with schizophrenia and 200 caregivers respectively. The 75 items of PRNQ-S-WX in the seventeen-factor solution and the 50 items of PRNQ-C-WX in the eight-factor solution accounted for 81.3% and 65.0% of the total variance respectively. In the qualitative study in the second phase, individual face-to-face semi-structured interviews were conducted with four urban and four rural consumers, and four urban and four rural caregivers. Using thematic analysis, the transcripts were analyzed by two independent coders. There were commonalities and discrepancies on their views about the unmet needs of rehabilitation interventions and community care, the disparities of healthcare resources for medication, the major factors hindering open employment, and the insufficient support to caregivers for facilitating recovery. These findings served as a triangulation to the quantitative survey in the third and last phase that consisted of a sample of 375 persons with schizophrenia and 250 caregivers to complete PRNQ-S-WX and PRNQ-C-WX respectively. The mean scores of the factors indicated the importance of the needs. Factors predicting the participants in the urban or rural regions were investigated by binary logistic regression. Ordinal regression was

adopted to test for the demographic variable(s) which determined the score in each of the factors having predicted the urban-rural categorization. “Psychosocial care” and “Behavior and impulse control” respectively predicted the urban-rural categorization of the consumers. Differences in the levels of the perceived importance in both factors were found across the employment status groups. The urban-rural categorization of the caregivers was predicted by “Security” and “Accommodation” respectively. Age was the demographics predicting the score in the factor “Security”. Some policy and service implications to promote psychiatric rehabilitation of the people with schizophrenia and their caregivers are discussed. With the original and insightful findings from the three phases, the central and provincial governments would be better informed to more precisely formulate or fine-tune the mental health policies and strategies to tailor needs-driven psychiatric rehabilitation services in China.

PUBLICATIONS ARISING FROM THE THESIS

1. Li, D., Tsui, M.C.M., & Tsang, H.W.H. (2014). Measuring perceived rehabilitation needs of caregivers of people with schizophrenia in mainland China. *Administration and Policy in Mental Health and Mental Health Services Research, 41*(3), 325-333.

2. Li, D., Tsui, M. C., Yuan, G. Z., Zhang, G., & Tsang, H. W. (2014). Measuring perceived rehabilitation needs of people with schizophrenia in mainland China. *Administration and Policy in Mental Health, 41*(5), 636-646.

3. Tsui, M.C.M., & Tsang, H.W.H. (2017). Views of people with schizophrenia and their caregivers towards the needs for psychiatric rehabilitation in urban and rural areas of mainland China. *Psychiatry Research, 258*, 72-77.

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Helping people in need has been my mission and passion. I believe that it can be achieved by clinical practices, education, and research. Over the past 14 years, my roles (sometimes sole and sometimes dual) as an occupational therapist in various clinical settings and a teacher in a number of tertiary institutes have taken up most of the time. Engaging in PhD study was an additional challenge for my time management. It was quite difficult for me to clearly identify the opportunity cost. Maybe it did vary with time. Perhaps it did not exist at all.

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TABLE OF CONTENTS

CHAPTER 1 INTRODUCTION

1.1. OVERVIEW OF STUDY

Schizophrenia affects as many as 24 million persons globally (World Health Organization, 2012) which has become a leading cause of short-term and long-term disabilities worldwide (Royal College of Psychiatrists, 2009). Its considerable consumption of mental health care resources results in a massive global burden of health finances (Bhugra, 2005). Schizophrenia constitutes over 60% of the 16 million people with severe mental illness in China (Phillips et al., 2009). It affects not only the patients but also the caregivers. Caregivers have a range of practical and emotional burdens such as sacrifice of time and high stress (Lowyck *et al.*, 2004) which compromise their quality of care (World Federation for Mental Health, 2010). Nevertheless, the needs of these two major stakeholders are ignored by the current mental healthcare system. Their quality of life is undermined as their needs are not adequately satisfied (Hansson *et al.*, 2003). Rehabilitation of individuals with schizophrenia is a main goal of mental health policy (Pillai et al., 2010). It is therefore necessary for the mental health policy to consider the perspectives of the major stakeholders involved (Jenkins, 2007). The rehabilitation needs perceived by the consumers and caregivers thus have to be investigated. It would assist the policy-makers to better allocate and prioritize resources for psychiatric rehabilitation services to satisfy the needs of the corresponding users (Wang *et al.*, 2012).

In China, psychiatric rehabilitation is still in its development stage. Available information on the rehabilitation needs of individuals with schizophrenia and their caregivers is very limited. As China is the hinderland of Hong Kong, the socio-cultural

values between these two regions are similar. The experiences of Hong Kong in conducting psychiatric rehabilitation research and providing the related services can be a valid reference to the mainland, in particular in those socio-culturally comparable regions such as Beijing, Shanghai, and Jiangsu. All of the three phases of this study were conducted in Wuxi which is a developed and urbanized city of the Jiangsu province. As of 2018, there are over 200,000 persons with schizophrenia in this province (Jiangsu Provincial Commission of Health and Family Planning, 2018). In addition to the societal and cultural contexts, Wuxi is also economically more comparable with Hong Kong. Its GDP ranked the ninth among other 956 major cities in the mainland in 2011 (Netherlands Business Support Office Nanjing, 2013). In 2014, its regional GDP was 820.531 billion RMB with a year-on-year growth of 8.2%, and its GDP per capita was 126,400 RMB with the growth of 7.9% (China Daily, 2015). In the same year, the GDP per capita in Hong Kong was about 270,000 RMB (Information Services Department, 2015). Although the difference in GDP per capita between Wuxi and Hong Kong seems significant, , it is predicted that with continuous economic growth in China both of them will probably become the top 100 metropolitan areas with the highest GDP per capita in the world (Cox, 2013). People with better economic status generally concern more about their quality of life and probably rehabilitation services for chronic diseases (Cummins, 2002). It is also true for those with mental illness and their caregivers who expect that the healthcare system should provide them with more tailored medical and rehabilitation services in order to maintain or improve their quality of life (Chang, 2014). Along this line, it is reasonable to investigate the rehabilitation needs of the two major stakeholders

in Wuxi to form a solid basis to more precisely formulate the corresponding psychiatric rehabilitation polices and services.

This study consists of three phases. The first phase is the validation of the two assessment tools originally developed in Hong Kong for measuring the perceived rehabilitation needs of the two major stakeholders, namely, individuals with schizophrenia and their caregivers respectively. Phase two is a qualitative study which explored the views of the two stakeholders in the urban and rural areas in Wuxi respectively towards the needs for psychiatric rehabilitation. Individual face-to-face semi-structured interviews were adopted with the questions derived from the results of the validation studies and the literature. Lastly, phase three is a survey using the two validated tools to measure and compare the perceived rehabilitation needs of the two stakeholders in the urban and rural areas in Wuxi respectively. The findings obtained collectively from these three phases have shed light on the directions for developing psychiatric rehabilitation services in Wuxi.

1.2. OBECTIVES OF STUDY

1. To examine the psychometric properties of the two questionnaires developed in Hong Kong, namely, The Perceived Rehabilitation Needs Questionnaire for People with Schizophrenia (PRNQ-S) and The Perceived Rehabilitation Needs Questionnaire for Caregivers of people with schizophrenia (PRNQ-C), for measuring the perceived rehabilitation needs for people with schizophrenia and their caregivers in urban and rural areas of Wuxi

2. To explore the views of people with schizophrenia and their caregivers towards the needs for psychiatric rehabilitation in urban and rural areas of Wuxi
3. To measure and compare the perceived rehabilitation needs of people with schizophrenia and their caregivers in urban and rural areas of Wuxi using the Wuxi version of the two questionnaires (PRNQ-S-WX and PRNQ-C-WX)
4. To propose directions for future development of psychiatric rehabilitation services and policies in mainland China

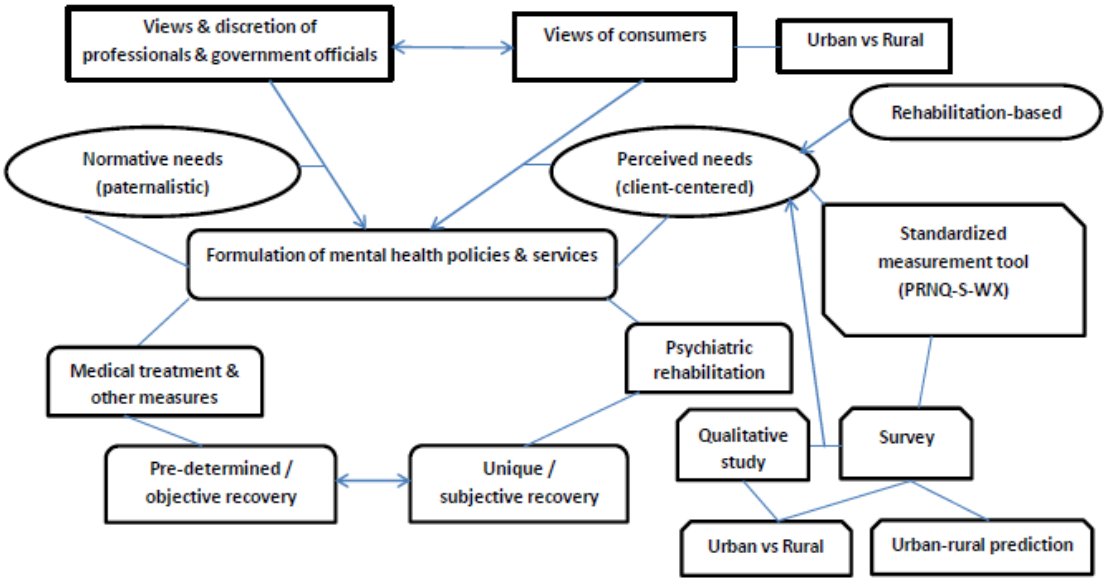
1.3. SIGNIFICANCE OF STUDY

The PRNQ-S and PRNQ-C originally developed in Hong Kong have already been validated in Wuxi. In psychiatric rehabilitation, these standardized tools are the first of its kinds in China. Through this cultural validation of the measurement scales, the perceived rehabilitation needs of people with schizophrenia and their caregivers in Wuxi and across the regions in the mainland can be more specifically contextualized. As an important means of triangulation, the qualitative study using individual semi-structured interviews has deepened the understanding on the two major stakeholders' awareness and evaluation on the various aspects of the psychiatric rehabilitation policy and services in the urban and rural areas of Wuxi. The investigation and comparison of their rehabilitation needs in the quantitative survey using PRNQ-S-WX and PRNQ-C-WX respectively can facilitate the review of the sufficiency and quality of the existing psychiatric rehabilitation policy and services in Wuxi. The findings of these three studies would collectively inform the central and provincial governments on the ways to formulate more precisely the mental

health policies and strategies to tailor needs-led psychiatric rehabilitation services. It would help satisfy the corresponding rehabilitation needs of the 10 million of people with schizophrenia and their caregivers in China and in turn contribute to enhancing their quality of life. With careful consideration of some potential socio-cultural differences, the findings can also serve as good references for the related policy makers, administrators, researchers and clinicians in other Asian-Pacific regions and the western countries.

Figure 1 illustrates the proposed improvement in the current mental healthcare system with the findings from the three phases of this study.

Figure 1
Proposed improvement in the formulation of mental health policies and services



CHAPTER 2 LITERTURE REVIEW

2.1. SCHIZOPHRENIA

2.1.1. OVERVIEW

Schizophrenia is a severe mental illness. While its exact etiology remains unknown, research findings support that genetic, neurological, psychological and environmental factors play a role on it. National Health Service (2014) provides a concise account of the factors. Genetically, if one of the identical twins develops this illness, the other twin will also have a 50% probability of developing it, even if they grow up separately. As for neurology, it may be the variations in the level of the two neurotransmitters, namely, dopamine and serotonin, which cause the disease. It may be an imbalance between the two neurotransmitters or a change in the sensitivity of the brain to them. Psychologically, stress such as that resulting from bereavement or unemployment is the significant trigger of the illness. Regarding the environment, social isolation and social disadvantages (such as poverty) have been found to be the risk factors.

In symptomology, schizophrenia is characterized by two main categories of symptoms, namely, positive and negative symptoms. The following denotes the two types of symptoms respectively:

Positive symptoms are the out-of-reality conditions including hallucinations and delusions (Carey, 2016). Hallucinations refer to the sensory experience that occurs without the presence of any sensory stimulus in which auditory hallucination is the commonest type that someone hears “voices” not actually existing (National Institute of

Mental Health, 2016). The voices may be internal or external that the former seems to originate from one's own mind, and the latter seems to be as authentic as someone is saying to him (Begley, 2002). The contents of the voices are usually negative such as commenting on a person's behavior or commanding him to do something dangerous (Nemade & Dombeck, 2016). Delusions refer to strongly held false (may be bizarre or persecutory) beliefs being inconsistent with one's culture which persist even with strong evidence disproving the logics (Rosner, 2000). For example, one can firmly believe that his colleagues want to control his mind by inserting an electronic device into his brain, or that someone doing good to him is actually a spy.

As for the negative symptoms, they are the disruptions to the normal emotions and behaviors including flat affect as shown in facial expression or voice tone, reduction of pleasure in daily life, and loss of motivation in initiating and sustaining daily activities (Greene, 2016).

As for the diagnosis of schizophrenia, the criteria based on the Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition (DSM-V; American Psychiatric Association, 2013) are as follows:

At least two of the following symptoms must have been experienced:

- Delusions
- Hallucinations
- Disorganized speech
- Disorganized or catatonic behavior
- Negative symptoms

At least one symptom must be delusions, hallucinations or disorganized speech.

Continuous signs of the disturbance must persist for at least six months, during which the person must experience at least one month of active symptoms (or less if successfully treated), with social or occupational deterioration over a significant time period. Any of such problems must not be attributable to another condition.

2.1.2. EPIDEMIOLOGY

The epidemiologic perspective has long been adopted to study schizophrenia so as to enhance the understanding of its dynamics in a population (McGrath et al., 2008). The following is a summary of the related statistics about some key epidemiological indicators including the prevalence, incidence, gender difference, age of onset, and relapse rate.

The prevalence of schizophrenia is approximately the same across countries which is about one percent of the population over the age of 18 (Picchioni & Murray, 2007). It has affected 24 million people worldwide as of 2011 (World Health Organization, 2011). It is estimated that the numbers of individuals with this illness in China, India and US are 12 million, 8.7 million and 2.2 million respectively (National Institute of Mental Health, 2016). In contrast, the incidence rates vary among countries. For example, the rate was 12/100,000 person-years in Netherlands (Sutterland et al., 2013) but higher in UK which was 15.2/100,000 person-years (Kirkbride et al., 2012). This disorder affects more males than females (1.4:1) (Aleman, 2003). The age of onset also differs between genders that men develop the illness earlier than women do. It starts

in the teenage in males but in the 20s or early 30s in females (Grohol, 2013). The overall relapse rate remains high worldwide. For instance, a longitudinal follow-up study in Hong Kong revealed that the relapse rates increased from 21% in the first year, then 33% in the second year and to 40% in the third year (Chen et al., 2005).

2.1.3. BURDENS

Various domains of burdens in schizophrenia exist which are serious and continuous in nature, and affect a number of parties including the consumers, caregivers and society. Investigating the burdens can lead to a better understanding of the impacts of schizophrenia on the health, healthcare, economics and policy (Knapp et al., 2004). The following is the analysis of the two main types of burdens from the two major perspectives, namely, economic and humanistic, respectively.

2.1.3.1. ECONOMIC BURDENS

There are economic costs of mental disorders. They cost over £105 billion in UK per year (Centre for Mental Health, 2010). The annual cost of schizophrenia alone is £6.7 billion (Mangalore & Knapp, 2007). The service costs including those for social and informal care are projected to be £32.6 billion in 2026 which is a 50% increase of that in 2007 (McCrone et al., 2008). In China, there has also been an increase in both the direct costs (such as medication) and the indirect costs (such as loss of productivity) of schizophrenia in Guangzhou from 2010 to 2012. The former rose from US 14.72 million

doubled to US 30.42 million, and the latter was from US 168.72 million to US 211.55 million (Guangzhou Municipal Statistics Bureau, 2012).

2.1.3.2. HUMANISTIC BURDENS

The literature on the humanistic burdens of schizophrenia is scarce as compared to that on the economic ones. A recent review (Millier et al., 2014) provides a comprehensive analysis of the humanistic burdens. These burdens are found to be serious and diverse which affect both the consumers and caregivers. Those induced on the consumers include functional impairment, stigmatization, homelessness, unemployment, social exclusion, depression, suicide, side-effects of antipsychotics, and hospitalization which collectively result in poor quality of life. Caregiver burdens are related to work overload, sleep disturbance, financial hardship, insufficient free time, discrimination, and social isolation. They not only undermine the caregivers' quality of life but also compromise the quality of care provision.

2.2. REHABILITATION FOR SCHIZOPHRENIA

2.2.1. PHILOSOPHY AND PRINCIPLES

Rehabilitation aims to enable individuals with disability to optimize their physical, psychological and social functional levels to achieve and maintain independence, self-determination and quality of life (World Health Organization, 2016). Similar to other types of severe mental illness, the rehabilitation for individuals with

schizophrenia utilizes pharmacological treatment for controlling the signs and symptoms, and psychosocial interventions for restoring psychological and social functioning (Meehan *et al.*, 2007). Along this line, the nature of the rehabilitation outcomes can be divided into objective and subjective. The objective indicator is the symptom remission, and the subjective one is the improvement in psychosocial functioning such as feeling of hope, discovery of meaning of life, and taking control and personal responsibilities (King *et al.*, 2007). Equal recognition of these objective and subjective dimensions of indicators and hence the corresponding strategies and interventions has been advocated (Deegan, 2003). In fact, some factors can contribute to both objective and subject recovery. Employment is an exemplar. It has long been proven that employment is beneficial to both the process and outcome of rehabilitation for people with schizophrenia (Tsang & Chen, 2007; Warner, 1985) which serves not only as an objective indicator in terms of the employment rate and job tenure but also as a subjective indicator in relation to successful social integration (Wilkinson & Marmot, 2003). The effectiveness of the implemented interventions can reinforce the recognition of the nature of the indicators. The Integrated Supported Employment (ISE; Tsang et al., 2009) is an excellent example. It is a vocational rehabilitation program for people with schizophrenia that integrates Individual Placement and Support (Drake & Becker, 1996) and Work-related Social Skills Training (Tsang & Pearson, 2001). It can help the participants attain both objective and subjective recovery. The objective recovery has been well illustrated by the positive outcomes including higher employment rate, longer job tenure, and symptom reduction as shown in a number of randomized controlled trials (Li et al., 2013c; Tsang et al., 2009; Zhang et al., in press). This demonstrates that employment rate and job tenure can also

fall into the objective indicators of recovery in addition to symptom reduction. Moreover, ISE contributes to subjective recovery. A recent qualitative study (Yu et al., 2016) reveals that the active participation in the ISE program to explore and gain employment is conducive to subjective recovery in Chinese societies. The case workers guided the participants to evaluate the efforts they paid in the process and compare their own meaning of work before and after the program. They became more aware through this review that they had taken personal responsibilities and control of their life as well as discovered their own meaning of life. It echoes with the literature that individuals with mental illness can never recover without regaining personal meaning and understanding of life (Glover, 2007). These gains lend further support to the development of vocational rehabilitation for people with schizophrenia in China.

2.2.2. POLICIES IN CHINA

Mental health policy is a well defined set of vision, core values, principles, and objectives for prioritizing actions to enhance mental health and alleviate burdens of mental illnesses in a population (World Health Organization, 2005). The strategies for successfully implementing the mental health actions have to be formulated based on the views of the service users which thus necessitate the investigation of their mental health needs (World Health Organization, 1998). It contributes to the fulfillment of one of the three core objectives which are to give due responses to the expectations of the consumers and caregivers in order to make the care both person-centered and needs-driven (World Health Organization, 2000). While mental health actions are not identical

across countries, a number of domains have been included in the majority of the mental health policies over the past decades in which rehabilitation to optimize the psychosocial functioning of the consumers is one of the key components (Government of Western Australia, 2004). Nevertheless, the policies in many countries heavily focus on psychiatric services which are confined to the medical treatment of mental illness but little (if not nothing at all) on rehabilitation and psychosocial rehabilitation interventions.

The situation seems to be better in China though various challenges exist. Prior to the first Mental Health Law enforced in 2013 (Standing Committee of the National People's Congress, 2013), there have already been the Mental Health Policy and Service Development Projects which aim to establish a monitor system to collect comprehensive information about the current mental health resources and the perceived needs of the main stakeholders (World Health Organization, 2001). For instance, the overall mission of the project implemented in the Jiang-Zhe province (where Wuxi is under) is to reinforce the coordination and management of mental health services. It has also formulated an intensive three-year mental health plan to comprehensively investigate the mental health needs and services to urge various stakeholders to systematically tailor-make and monitor their own mental health service plans. In the modernization process, China has also attempted to formulate policies for enhancing the mental health of the people in both urban and rural regions (China Development Research Foundation, 2005). Nevertheless, psychiatric rehabilitation is severely under-funded that the spending on mental health is even less than 1% of the total health expenditure (Patel et al., 2015). Worst still, the related development is complicated by the health inequality between the more developed urban areas and the less developed rural areas as a result of continuous

socio-economic revolution (Griffiths, 2008). In fact, such disparity has remained wide in the mainland due to insufficient financial resources and their imbalanced allocation. The disproportionate allocation is so obvious that 70% of the total population live in the rural areas but as high as 80% of the total health expenditure is put to the urban areas (Shi and Gong, 2005). The mental health service system has been timely established in the rich coastal regions but not in the under-developed western regions (Liu et al., 2011). Under the economic reform, the concepts of market economy have encouraged the hospitals (no matters they are general and psychiatric) to make profits (Li et al., 2005). Nearly all of the hospitals are built in the richer urban places because their services target at those users who can afford financially (Philips, 2000). The better social insurance system there also catalyzes the use of the hospital services (World Health Organization, 2010). In contrast, the situations are worrisome in the rural areas. Psychiatric hospital beds do not exist in even two-thirds of the rural districts (Patel et al., 2016). The skewed availability of the expensive hospital services in the urban areas makes the rural users inaccessible to the services they need due to their economic disadvantage and long geographical distance. In fact, they are in the greatest need for affordable healthcare as neither the service provision nor the social insurance coverage there is adequate. It is therefore not surprising to find in a recent study in Wuxi that financial burdens existed in the rural areas but not in the urban areas (Tsui & Tsang, 2017). The median total healthcare cost for schizophrenia in 2010 has already been as high as ¥10,765 per hospital admission (Montgomery et al., 2013) but its GDP per capita was merely ¥51,711 (Global Times, 2012). Medical insurance coverage for all (i.e., universal coverage) may help lessen the problems. However, despite great efforts the expansion rate of the coverage in China

cannot outweigh its increased rate of people with mental illness (Deloitte, 2015). Moreover, the mental health polices have been influenced by the traditional Chinese culture (Chow, 2006). As family caregivers in Chinese societies are expected to take care of the family members in particular when they are either physically or mentally ill, the government has shifted the caring responsibility to them without providing due support (Wong et al., 2012; Yip, 2005). For instance, over 70% of the 427 caregivers received no help from others (Yin et al., 2014). It is thus of no surprise to note that there is no policy targeting at addressing the caring burdens of family caregivers (Chang et al., 2017).

2.2.3. PRACTICES IN CHINA

Advancement in the concepts and practices of psychiatric rehabilitation in Hong Kong is apparent. It is however not that favorable in mainland China. In addition to the physiological basis, the adoption of psychosocial perspective in viewing the nature and hence the management of schizophrenia has increasingly gained recognition in Hong Kong (Lee & Yiu, 2013). The launch of the psychosocial rehabilitation services in Integrated Community Centers for Mental Wellness under the Social Welfare Department highlights the adoption of strengths-based model in practice (Hui et al., 2016). Instead of pinpointing the weaknesses or deficits induced by the illness, this model focuses on the strengths of the individuals including having good family support to help them go through the recovery journey (Rapp & Goscha, 2011). This clearly illustrates a paradigm shift from the traditional disease model emphasizing symptom alleviation to the contemporary recovery model targeting optimization of quality of life through living with

instead of living against the illness (Andresen et al., 2003). In contrast, the traditional medical model of care characterized by prolonged hospitalization with pharmacotherapy remains dominant in the mainland (Li et al., 2014b). In fact, it is due to the various challenges in fostering psychiatric rehabilitation philosophy and practices in China. Although it is stipulated in Chapter IV (Rehabilitation of mental disorders) of the China's New Mental Health Law (Standing Committee of the National People's Congress, 2013) that rehabilitation interventions for persons with mental illness should be provided, it seems that the development of the related services has been lagging behind. As there has been a shift of the rehabilitation mode from traditional hospital-based to contemporary community-based (Sibbald et al., 2007), the policy makers should consider sharpening the strategies to enable community-based settings to facilitate community reintegration of persons with schizophrenia. The community-based rehabilitation aims to promote the quality of life of the consumers through social inclusion by using the concerted efforts of the stakeholders including the individuals themselves and their families together with the community social and rehabilitation service providers (World Health Organization, 2004). Nevertheless, not until recently is there a systematic evaluation of factors determining the success of community integration. Despite some limitations on methodology, The Asia Pacific Mental Health Index may serve as a good reference. It is developed by the Intelligence Unit of Economist to assess and rank 15 selected Asia-Pacific regions (namely, China, Hong Kong, Taiwan, Singapore, South Korea, Japan, Thailand, Malaysia, Vietnam, Philippines, Indonesia, India, Pakistan, Australia and New Zealand) on a total of 18 indicators critical for facilitating integration into the community for persons with mental illness (The Economist, 2016). The 18 indicators are categorized

into four domains, namely, Environment (five indicators), Access to treatment (five indicators), Opportunities (three indicators), and Governance (five indicators). Environment is the degree to which a policy supports those with mental illness to lead a normal life, and it includes indicators such as the support to family and caregivers. Access to treatment is about the availability of health services, in which access to medication and therapy is one of the indicators. Opportunities refer to the extent to which a policy facilitates the consumers to engage in employment, and its indicators include return-to-work schemes. Governance pertains to the efforts of a healthcare system to combat stigma and promote human rights of the service users, and one of the indicators is the collection of consumers' opinions about the mental healthcare quality. The score is from 0 to 100 in each domain and in overall one, with higher ones indicating better standards. In fact, these four domains match very well with the philosophy and practices of psychiatric rehabilitation. In other words, they are central to the success of psychiatric rehabilitation. The overall score of China is 45.5 and it ranks the ninth among the regions (followed by Thailand, India, Philippines, Vietnam, Indonesia and Pakistan respectively). Half of the domains, namely, Opportunities, and Access to treatment, are scored below 50.0, and they are 38.9 and 27.4 respectively. The other two domains are relatively better, with Environment scored 60.0 and Governance 53.3. Comparing with the other two Chinese societies, Hong Kong and Taiwan, China has lowest scores overall and in each of the four domains. This echoes quite well with the above discussion that the development of psychiatric rehabilitation in China lags behind in terms of the concepts and practice. In fact, China should be more aware of the fact that the non-governmental organizations play crucial roles in mobilizing various social resources and hence

providing substantial and sustainable community rehabilitation services such as psychotropic medication, vocational rehabilitation, support to caregivers, and anti-stigma campaigns to facilitate the recovery of persons with mental illness (Liu et al., 2011). Although these services are regarded as crucial, no sufficient scientific research has been conducted to guide the development and implementation. For instance, cost-utility analysis on anti-psychotics is necessary which helps provide financially sustainable rehabilitation services (World Health Organization, 2007). Unfortunately, related study is scarce in China. This may account for its very low score (27.4 out of 100) in the domain of Access to treatment in the Index. The score is not much higher in the domain of Opportunities (53.3) which is about the degree to which the policy facilitates the consumers to return to work. Undeniably, the vocational rehabilitation in China is still in the development stage (Li et al., 2014a). In fact, employment is one of the critical social determinants of mental health (Wilkinson & Marmot, 2003). Social determinant of health is a public health concept which refers to any factor in social contexts such as education, employment, and income contributing to one's health status (Commission on Social Determinants of Health, 2008). Among them, employment is particularly crucial to persons with schizophrenia which has long been proven to protect mental status and contribute to community integration, and thus conducive to both the course and outcomes of the recovery (Tsang & Chen, 2007). Unfortunately, the unemployment rate in this clientele remains high in both urban and rural areas of mainland China (Montgomery et al, 2013). Public health approach is indeed not new to the healthcare system in China. There is however a lack of public health interventions tailored to tackle the unemployment issues in persons with schizophrenia (Zhang et al., 2016). It is observed

that the strategies of public anti-stigma campaigns are still confined to the promotion of the understanding of schizophrenia and the clarification of its related myths. While it may indirectly help increase the employers' willingness to hire persons with schizophrenia, employment per se has not yet been recognized as a social determinant of mental health and hence community integration. As a result, advocacy of promoting the mental health of people with schizophrenia through employment has not been put into the public health agenda (World Health Organization, 2003). In view of such deficiency as reflected in the current healthcare system, it is worthwhile to explore the feasibility of integrating mental health and public health practices in mainland China by enabling collaboration between psychiatric rehabilitation professionals and public health experts to foster the conceptualization and practice of public mental health to address the mental illness stigma and enhance the employment outcomes (Shim & Rust, 2013).

Besides, while combating stigma is regarded to be necessary in mainland China, little is known about how to reduce it. It is not uncommon to find that stigma occurs once others know a person's mental illness, and rejections against him will then start and persist even after the symptoms have subsided (Byrne, 2000). It indeed induces huge barriers in fulfilling one's social roles by having successfully engaged in the expected tasks such as work (Thara et al., 2008). This can also account for its prolonged low employment rate in the individuals with schizophrenia. Worse still, the consumers may also have self-stigma that they are self-discredited through internalizing negative stereotypes induced to him and/or his illness group by the public (Corrigan & Watson, 2002). Some research has been conducted in Hong Kong to uncover the mechanisms and yield evidence to guide the corresponding interventions. Severe self-stigma is found to

significantly hinder treatment compliance (Fung et al., 2007). The mechanism of the self-stigmatization process (Corrigan et al, 2006) is three-tier, namely, stereotype agreement (with the negative characteristics of persons with schizophrenia such as danger and violence), self-concurrence (believing those negative stereotypes induced), and self-esteem decrement (through further internalizing of what they believe about those stereotypes). Those who are more seriously self-stigmatized tend more to endorse their feeling of hopelessness (a negative stereotype agreement) and thus think that they cannot benefit from the treatment at all and so simply do not adhere to it. There are a number of interventions to address the issues. In population-based practice, interventions to tackle public stigma on mental illness have to be incorporated into mental health policy (Jenkins, 2003). Campaigns to fight against public stigma can serve to lessen the stereotype agreement (the first of the three-tier mechanism of the self-stigmatization process). Nevertheless, their cost-effectiveness is questionable. Their large-scale nature requires high costs and many complex variations (such as the degree of match between mass media strategies and target audience's characteristics) may eventually hinder the success of the programs (Li et al., 2013). Instead, individual-based interventions targeting at those with schizophrenia who are self-stigmatized may be a way out. As higher level of self-stigma is associated with poorer adherence to the interventions, reducing self-stigma may contribute to improving the treatment compliance. The first self-stigma reduction program in the entire mainland China is developed in Hong Kong which utilizes various strategies such as psychoeducation, cognitive behavioral therapy, social skills training, and motivational interviewing (Fung, 2010). This program was found in a randomized controlled trial to be effective for reducing self-stigma of the participants and enhancing

their readiness for managing problematic behaviors (Fung et al., 2011). It is thus worth considering adopting this program in the mainland. Further efforts should be paid to validate the program with reference to the socio-cultural contexts, and then investigate its effectiveness in practice.

In addition to the factors discussed above, the shortage of the manpower of mental health professionals remains the critical issue in the community integration of people with schizophrenia in mainland China (Li et al., 2014b). The bio-psycho-social nature of schizophrenia requires multi-disciplinary management and the input from various professionals including psychiatrists, psychiatric nurses, occupational therapists, social workers and psychologists. Unfortunately, this multi-disciplinary team has not ever existed as the availability of the latter three members remains very limited. While psychiatrists and psychiatric nurses are specialized in pharmacotherapy, they may not have clear concepts of psychosocial rehabilitation and hence the actual practices such as community living skills training, social skills training, and supported employment programs (Li et al., 2014a) which are the expertise of psychosocial professionals including occupational therapists, social workers, and psychologists. In other words, the launch of the suitable psychosocial interventions is hampered by the lack of full-wing workforce. The limited availability of those psychosocial professionals in the mainland is due to at least two reasons. Historically, the fertilization stage of psychiatry in 1950s was influenced by some political force which prohibited the instillation of social sciences such as sociology and psychology and thus the nurture of the related professionals (Pearson, 1995). Currently, despite the steadily growing recognition of the psychosocial professions, the scarcity of mental health resources makes it difficult for the field to

either invite overseas experts to locally train up the new breeds of the professionals or recruit skilled practitioners elsewhere into the workforce (Li et al., 2014b). For example, the salary of a middle-level occupational therapist in Hong Kong can be as high as the double of that of a consultant psychiatrist in Wuxi. All in all, pharmacotherapy provided by psychiatrists and mental health nurses continues to be the only treatment modality. It is not surprising to find that symptom remission seems to remain the only indicator of the objective recovery (Zhang et al., 2016). In fact, as stated earlier, a number of subjective indicators of recovery including feeling of hope, discovery of meaning of life, taking control and personal responsibilities, reconstructing lifestyle, and establishing connections with others, should also be taken into account when planning, implementing and evaluating psychiatric rehabilitation services (King et al., 2007). Overall, psychiatric rehabilitation in China remains undeveloped in the absence of psychosocial interventions.

The above discussion reveals that the psychiatric rehabilitation of the people of schizophrenia in China has never been satisfactorily enforced. It is expected that needs-driven policies and interventions will help facilitate its implementation and hence enhance the outcomes by better allocating and prioritizing the related resources. Along this line, integrating the opinions of individuals with schizophrenia and their caregivers as the major service users for mental health service development is very reasonable and thus necessary (World Health Organization, 2004). Through cross-referencing with the professional knowledge bases in psychiatric rehabilitation currently dominant in China, the additional and first-hand perspectives from the two groups of service users can enrich the existing body of knowledge.

2.2.4. PERCEIVED REHABILITATION NEEDS

2.2.4.1. NEEDS AND NEEDS ASSESSMENT

It is essential to understand the concept of need before planning and managing any health services including health promotion, resource allocation, and equity (Steinbach, 2009). There are four types of social need as categorized by Bradshaw (1972), namely, normative need, perceived need, expressed need, and relative need. Normative need refers to the standards or criteria established by custom, authority or general consensus. Perceived need is what people think or feel. When this kind of perceived need is turned into action such as seeking help, it is called expressed need. As for relative need, it is the gap between the level of services in one community and that in other similar communities. Scientific measurement of needs is the key to successfully implementing the corresponding health services. According to Bindra (2008), needs assessment in health refers to a systematic process to identify the unmet needs of health and healthcare in a population, and to initiate changes to meet those unmet needs through reallocating resources, and partnering with communities, service providers and service users. It also serves to engage the stakeholders in the service development and hence promote the ownership and sustainability of the health policies and services. Identification of the needs of the consumers and their significant others including their caregivers is the first and foremost step in the rehabilitation process (Steiner et al., 2002). As for psychiatric rehabilitation, exploration of the perceived needs of people with schizophrenia and their caregivers towards rehabilitation is crucial for building effective psychiatric rehabilitation systems and services (Yeh et al., 2011). Neither normative needs nor relative needs are focused in this study. Normative needs emphasize

professionals' discretion instead of users' autonomy and determination as they stem from paternalism that mistakenly assumes that healthcare professionals share the same values and expectations with the end users on health services. Similarly, finding out the gap between the level of services in one community and that in other similar communities as what the relative needs denote seems not helpful enough due to deviations from the users' own choices and preferences. In the following two sub-sections, the two standardized needs assessment tools developed in Hong Kong to measure the rehabilitation needs of persons with schizophrenia and their caregivers respectively will be described separately. As mentioned earlier, these two tools have formed a skeleton of the entire study.

2.2.4.2. INDIVIDUALS WITH SCHIZOPHRENIA

There are a number of related needs assessment instruments in the field. The most popular one is the Camberwell Assessment of Need (CAN; Phelan et al., 1995). Despite its comprehensiveness (with 22 areas of needs), its specificity has to be further enhanced. Elaboration of the corresponding dimensions in each area is needed. For example, Wong et al. (2011) suggested that the area "vocational needs" had to be made more specific as it could mean many possible yet unspecific domains such as job opportunities, work-related social skills, or relationships with co-workers. Another instrument, the Medical Research Council Needs for Care Assessment (MRC-NCA; Nielsen et al., 1999), is based on the perspectives of the experts but not the consumers. As a result, the actual perceived needs of persons with schizophrenia cannot be validly evaluated. The St Louis Inventory of Community Living Skills (SLICLS; Evenson & Boyd, 1993) also tends to focus

primarily on the clinical outcomes rather than the perceived needs. On the contrary, the tool validated in Phase One of this study provides in-depth information about the multi-dimensional components of each of the domains stemming directly from the perceived needs. It is called the Perceived Rehabilitation Needs Questionnaires for People with Schizophrenia (PRNQ-S; Wong *et al.*, 2011) (Appendix I) which is the instrument originally developed in Hong Kong to measure the perceived rehabilitation needs of persons with schizophrenia.

This tool is composed of three sections. Through face-to-face interview, a trained assessor administers the questionnaire to the respondent with schizophrenia. The first section contains 75 items to assess the respondent's perceived importance of the rehabilitation needs. These items were generated using thematic analysis from the results of six focus group discussions with three stakeholders including 14 persons with schizophrenia, 13 caregivers, and 16 mental health professionals respectively. The items are finally grouped into 17 factors according to the loadings of each factor. These loadings are called factor loadings. A factor loading represents how much a factor explains a variable in factor analysis, and it ranges from -1 to 1, with that close to -1 or 1 indicating that the factor significantly affects the variable, and that close to zero indicating that the factor weakly affects on the variable (Minitab, 2016). In descending factor loadings, the 17 factors include Occupation, Social welfare and security, Medical services, Family, Social and intimate relationship, Behavior and impulse control, Symptom management, Right for treatment, Discrimination, Housing, Self care, Stress management, Leisure, Education, Care for children, Treatment compliance, and Lifestyle. The respondent is asked to rate his perceived importance of the need in each item using a

five-point Likert scale, with 1 denoting ‘never important’, 2 denoting ‘seldom important’, 3 denoting ‘sometimes important’, 4 denoting ‘usually important’, and 5 denoting ‘always important’. The respondent is also required to rate to what extent his need is satisfied in each item if he has ever received the corresponding service(s), following a five-point Likert scale, with 1 denoting ‘never satisfied’, 2 denoting ‘seldom satisfied’, 3 denoting ‘sometimes satisfied’, 4 denoting ‘usually satisfied’ and 5 denoting ‘always satisfied’.

The second section requires the respondent to rate his perceived importance of various psychiatric rehabilitation services using a five-point Likert scale, with 1 denoting ‘never important’, 2 denoting ‘seldom important’, 3 denoting ‘sometimes important’, 4 denoting ‘usually important’ and 5 denoting ‘always important’. The selection of the services was based on an expert panel consisting of eight experienced mental health professionals. There are a total of 30 items which are divided into eleven categories including Vocational rehabilitation, Community rehabilitation, Family intervention, Residential placement, Psychotherapy, Psychotropic medication, Self management program, Social activity, Social welfare, Emergency service, and Others. Similarly, the respondent also has to rate to what extent his need is satisfied in each item if he has ever received the corresponding service(s), using a five-point Likert scale, with 1 denoting ‘never satisfied’, 2 denoting ‘seldom satisfied’, 3 denoting ‘sometimes satisfied’, 4 denoting ‘usually satisfied’, and 5 denoting ‘always satisfied’. An open-ended question is included for recording the respondent’s opinions towards the rehabilitation needs or service provision.

In the final section, the respondent is asked to provide his own demographic information for analysis including descriptive statistics and inferential statistics.

This tool has good internal consistencies and intra-rater reliability (Wong et al. 2011). The high coefficient alpha of the total score (0.91) indicates that the items in the subscales measure the same construct. The high ICC coefficient of the total score (0.88) represents good stability of the tool over time.

2.2.4.3. CAREGIVERS

Three related needs assessment tools, namely, the Needs for Care Assessment Schedule (NFCAS; Mac Carthy et al., 1989), the Relatives' Cardinal Needs Schedule (RCNS; Barrowclough et al., 1998), and the Carers' Needs Assessment for Schizophrenia (CNA-S; Wancata et al., 2006), are available in the field. NFCAS is a brief appendix which lists out only seven areas of problems encountered by the caregivers. In addition to the question on its non-comprehensiveness, its perspective is that of the experts instead of the caregivers and thus it cannot validly reflect the actual needs perceived by the latter. As for RCNS, there is also room for enhancing the comprehensiveness as only several issues are addressed in its current version. Besides, its design is problem-oriented which focuses on the problems facing the caregivers instead of exploring their needs. Similarly, CNA-S is also problem-focused but not need-focused. In contrast, another needs assessment instrument validated in Phase One of this study, namely, Perceived Rehabilitation Needs Questionnaires for Caregivers of People with Schizophrenia (PRNQ-C; Li *et al.*, 2014a), contains more domains in a comprehensive way which are

based on the perceived importance of the needs. Originally developed in Hong Kong, PRNQ-C (Appendix II) is to measure the perceived rehabilitation needs of caregivers of persons with schizophrenia.

There are three sections. A trained rater administers the questionnaire via face-to-face interview with the respondent who is a caregiver of a person with schizophrenia. The first section is composed of 50 items for assessing the respondent's perceived importance of various rehabilitation needs as a caregiver. These items were generated using thematic analysis from the results of two focus group discussions with 13 caregivers regarding their needs about taking care of relatives with schizophrenia. The items are finally grouped into eight factors according to the factor loadings. In descending order, they are Stress management, Security and Caring skills, Leisure and Social life, Burden reduction, Social support, Financial support, Work and Accommodation, and Discrimination reduction. The respondent is asked to rate his perceived importance of needs in each item following a five-point Likert scale, with 1 denoting 'never important', 2 denoting 'seldom important', 3 denoting 'sometimes important', 4 denoting 'usually important', and 5 denoting 'always important'. The respondent is also asked to rate to what extent his need is satisfied in each item if he has ever received the corresponding service(s), using a five-point Likert scale, with 1 denoting 'never satisfied', 2 denoting 'seldom satisfied', 3 denoting 'sometimes satisfied', 4 denoting 'usually satisfied' and 5 denoting 'always satisfied'.

The second section requires the respondent to rate his perceived importance of various psychiatric rehabilitation services with a five-point Likert scale, with 1 denoting 'never important', 2 denoting 'seldom important', 3 denoting 'sometimes important', 4

denoting ‘usually important’ and 5 denoting ‘always important’. The selection of the services was based on an expert panel consisting of eight experienced mental health professionals. A total of 12 items are divided into seven categories, namely, Family rehabilitation, Psychotherapy, Self management, Social activity, Social welfare, Emergency services, and Others. Similarly, the respondent is also requested to rate to what extent his need is satisfied in each item if he has ever received the corresponding service(s), following a five-point Likert scale, with 1 denoting ‘never satisfied’, 2 denoting ‘seldom satisfied’, 3 denoting ‘sometimes satisfied’, 4 denoting ‘usually satisfied’, and 5 denoting ‘always satisfied’. An open-ended question is included for the respondent to write down his opinions towards the rehabilitation needs or service provision.

In the final section, the respondent needs to provide his own demographic information for analysis including descriptive statistics and inferential statistics.

This tool has satisfactory internal consistencies and intra-rater reliability (Li et al. 2014a). The coefficient alpha ranged from 0.83 to 0.91 for the first five factors, and from 0.63 to 0.73 for the other three factors. It represents that the items in the subscales measure the same construct. The ICC coefficients were high which ranged from 0.75 to 0.88 (except one factor that was 0.52). It indicates overall good stability of the tool over time.

2.2.5. THE WAY FORWARD IN CHINA

Given the complexity of the psychiatric rehabilitation per se and of its associated issues specific to mainland China, evidence governing its conception and implementation is of utmost importance. Mental health policy research thus has to be supported by China government for formulating evidence-based psychiatric rehabilitation policies and practices relevant to its unique socio-cultural contexts (Liu et al., 2011). Scientific measurement of the rehabilitation needs of people with schizophrenia and their caregivers through standardized assessment tools is the key to systematically understanding the areas of concerns. Exploration of their concerns about psychiatric rehabilitation through qualitative approach can help figure out the underlying reasons. By comparing the rehabilitation needs between the two stakeholders, the discrepancies which may have undermined the rehabilitation outcomes can be revealed, and hence addressed by sharpening the corresponding intervention strategies. This three-tier framework has constituted the flow and scope of this research study which is expected to contribute to filling the existing knowledge gap about the ways to tailor psychiatric rehabilitation policies and services in China.

CHAPTER 3: MAIN STUDIES

3.1. PHASE ONE: CULTURAL VALIDATION OF PRNQ-S AND PRNQ-C

3.1.1. INTRODUCTION

As discussed earlier in Chapter One, the experience in developing psychiatric rehabilitation services in Hong Kong can serve as a valid reference to the mainland, in particular those better developed regions such as Wuxi. Although Hong Kong and the mainland share the same historical and cultural root, the former had been under the rule of United Kingdom for over 150 years and thus influenced by western cultures. It is not surprising to note various differences between the two places. There is no exclusion for the mental health issues. The modernization of China does not only promote its economic growth but also formulate policies for balancing the development among the urban and rural areas, and creating more employment opportunities (China Development Research Foundation, 2005). Hong Kong is a society which is laissez-faire and capital in nature. Its immature healthcare system causes some problems. In mainland China, the situations are even worse due to the health inequality between the people in the more developed urban regions and those in the less developed rural regions because of the ongoing social and economic revolution (Griffiths, 2008). For instance, formal psychiatric treatment services are almost exclusively provided in the urban areas but only until quite late some become available in certain rural regions now (Philips, 2000). The inadequacy of the healthcare resources for the psychiatric rehabilitation services further hampers the efficiency in the allocation of the resources and hence the accessibility to the related services (Fitzner, 2000). Given the differences in service provision and model of delivery in psychiatric

services, developing provincially validated assessment tools for measuring and hence understanding the perceived rehabilitation needs of the service users including the consumers and caregivers is the key to tailoring province-specific mental health policies and services. This phase of the study aimed to validate the Hong Kong version of PRNQ-S (PRNQ-S-WX) and PRNQ-C (PRNQ-C-WX) to be adapted in Wuxi, using expert panel method and exploratory factor analysis.

3.1.2. METHOD

3.1.2.1. PARTICIPANTS

3.1.2.1.1. INDIVIDUALS WITH SCHIZOPHRENIA

A total of 250 participants recruited from Wuxi Mental Health Centre by convenience sampling were invited to complete the PRNQ-S-WX. They were the persons with schizophrenia for at least one year according to the diagnosis made by case psychiatrist based on the criteria of DSM-IV. They were symptomatically stable, aged 18 or above, and fluent in Putonghua. Anyone failing to understand or express clearly was excluded. The demographic information of the respondents in Wuxi and Hong Kong is summarized in Table 1.

Table 1
Demographic information of the participants in PRNQ-S-WX and PRNQ-S-HK

Frequency (Percent)	PRNQ-S-WX *n*=250	PRNQ-S-HK *n*=219	*p*
Gender			
Male	123 (49.2%)	116 (53.0%)	
Female	127 (50.8%)	103 (47.0%)	.387
Age			
18-25	30 (12.0%)	10 (4.6%)	
26-35	60 (24.0%)	52 (23.7%)	
36-45	76 (30.4%)	69 (31.5%)	
46-55	53 (21.2%)	63 (28.8%)	
56 or above	28 (11.2%)	25 (11.4%)	.032
Educational level			
Illiterate	3 (1.2%)	3 (1.4%)	
Primary	47 (18.8%)	53 (24.2%)	
Secondary	160 (64.0%)	147 (67.1%)	
Tertiary or above	38 (15.2%)	16 (7.3%)	.015
Marital status			
Single	103 (41.2%)	122 (55.7%)	
Married	119 (47.6%)	70 (32%)	
Divorced	23 (9.2%)	23 (10.5%)	
Widowed	4 (1.6%)	4 (1.8%)	.014
Living condition			
Live alone	23 (9.2%)	46 (21.0%)	
With family members	223 (89.2%)	170 (77.6%)	
Half way House	0 (0.0%)	3 (1.4%)	
Others	4 (1.6%)	0 (0.0%)	<.0001
Employment status			
Open employment	85 (34.0%)	63 (28.8%)	
Supported employment	4 (1.6%)	5 (2.3%)	
Shelter Workshop	2 (0.8%)	8 (3.6%)	
Unemployed	113 (45.2%)	143 (65.3%)	
Others	45 (18.0%)	0 (0.0%)	.084
Length of contacting mental health service			
2 years or below	27 (10.8%)	14 (6.4%)	
2 – 5 years	54 (21.6%)	38 (17.4%)	
5 – 10 years	74 (29.6%)	59 (27.1%)	
10 years or above	92 (36.8%)	108 (49.1%)	.005

3.1.2.1.2. CAREGIVERS

By convenience sampling, a total of 200 participants recruited from Wuxi Mental Health Centre were invited to complete the PRNQ-C-WX. They were the caregivers of persons with schizophrenia and had taken up the caring role for at least one year. They were aged between 18 and 60, and fluent in Putonghua. Anyone who could not understand or express clearly was excluded. Table 2 summarizes the demographic information of the respondents in Wuxi and Hong Kong.

Table 2
Demographic information of the participants in PRNQ-C-WX and PRNQ-C-HK

	PRNQ-C-WX	PRNQ-C-HK	
Frequency (Percent)	*n* = 200	*n* = 98	*p*
Gender			
Male	95 (48.0%)	38 (38.8%)	
Female	103 (52.0%)	60 (61.2%)	.327
Age			
18-25	7 (3.5%)	3 (3.1%)	
26-35	27 (13.5%)	11 (11.2%)	
36-45	64 (32.0%)	14 (14.3%)	
46-55	56 (28.0%)	26 (26.5%)	
56 or above	46 (23.0%)	44 (44.9%)	.001
Educational level			
Illiterate	2 (1.0%)	6 (6.1%)	
Primary	49 (25.0%)	37 (37.8%)	
Secondary	95 (48.5%)	48 (49.0%)	
Tertiary or above	43 (21.9%)	7 (7.1%)	
Others	7 (3.6%)	0 (0.0%)	.151
Marital status			
Single	14 (7.0%)	14 (14.3%)	
Married	158 (79.4%)	69 (70.4%)	
Divorced	13 (6.5%)	8 (8.2%)	
Widowed	14 (7.0%)	7 (7.1%)	.480
Living with patient			
Yes	175 (89.3%)	76 (77.6%)	
No	21 (10.7%)	22 (22.4%)	.162
Employment status			
Employed	142 (71.0%)	38 (38.8%)	
Unemployed	58 (29.0%)	60 (61.2%)	.000**
Length of contacting mental health service			
2 years or below	15 (7.5%)	14 (14.3%)	
2 – 5 years	57 (28.5%)	23 (23.5%)	
5 – 10 years	52 (26.0%)	18 (18.4%)	
10 years or above	76 (38.0%)	43 (43.9%)	.834

3.1.2.2. INSTRUMENTS

3.1.2.2.1. EXPERT PANEL METHOD

3.1.2.2.1.1. OVERVIEW

Expert panel method was used to ascertain the cultural relevancy of the items of the Wuxi version of PRNQ-S-HK and PRNQ-C-HK respectively. This method is adopted when professional input and opinions are to be sought from experts based on their

expertise to contribute to various works by making recommendations such as that in questionnaire evaluation (Laidlaw, 2014).

3.1.2.2.1.2. METHOD

The expert panel in these two studies was identical which was composed of the healthcare professionals with the following two inclusion criteria: 1) a rehabilitation or health care professional qualification (such as rehabilitation, medicine, nursing); and 2) at least five years of experience working with persons with mental illness. A total of 15 invitation letters together with the two tailor-made questionnaires were sent to the eligible persons. The questionnaire for PRNQ-S-HK included a set of its items with the columns next to each indicating the options of “relevant”, “neutral”, and “irrelevant” respectively. The design of that for PRNQ-C-HK was the same. Each of the panel members was asked to independently comment on the cultural relevancy of each of the items of the two measurement tools respectively to be used in Wuxi. They needed to give reason(s) if they marked any items as either “neutral” or “irrelevant”. A total of 15 experienced mental health professionals (five psychiatrists and ten mental health nurses) were finally recruited. The response rates of the both sets of the questionnaires were 100% and all of them were validly completed. Content Validity Ratio (CVR) was used to assess the agreement on the cultural relevancy of each item among the expert panel members (Lawshe, 1975). The CVR is a ratio ranging from +1 (agreed by all members) to -1 (disagreed by all members). Positive values mean that at least half of the panel members agree that the item is relevant while negative values mean that fewer than half do so. The

CVR is equal to $(n_e – N/2) / (N/2)$ where n_e is the number of the panel members agreeing the item as relevant, and N is the total number of the panel members. If, for instance, 11 out of the 15 panel members mark the item as relevant and the remaining four mark it as either neutral or irrelevant, the CVR will be equal to (11 – 15/2) / (15/2) which is +.47, with the positive sign indicating that more than half of the panel members agree that the item is relevant. The critical value of CVR with reference to the number of panel members is to be attained to ensure that the agreement is not due to chance. The critical value was +.49 for the panel size of 15 in this study.

3.1.2.2.1.3. RESULTS

In the questionnaire for PRNQ-S-HK, all except two items were scored +1. It indicated that each of those items respectively was totally agreed by the panel as relevant. The total agreement was however not attained in the two items. A focus group (with nine psychiatrists and 17 mental health nurses from Wuxi and two occupational therapists from Hong Kong) was then formed and discussed the two items. One item was scored -.33 in which ten panel members did not agree with the use of the term “qigong”. The negative value indicated that fewer than half of the panel members regarded it as relevant. They criticized qigong on its questionable therapeutic values. Clarification was made by the focus group and the term “mind-body exercise” was finally used instead. The other item was scored +.20 in which six panel members disagreed with the use of the term “religion”. They argued that religion was not suitable for individuals with schizophrenia. It might be due to their poor understanding of the potential therapeutic

values of religions in psychological well-beings. It might also be related to some political reasons that certain religions might be regarded as some means of dissemination of anti-government messages. To strike a balance, the term “spiritual activities” was ultimately adopted. Finally, no item was deleted.

As for the questionnaire for PRNQ-C-HK, all except three items were scored +1 meaning a total agreement by the panel as relevant. The same focus group discussed each of the three items. One panel member had a neutral view on the term “half-way house” in an item (CVR = +.87). The focus group found that it was related to the difference in the terminology between the two regions. It was then agreed that the conventional term in Wuxi should be used. The second item was scored +.33 that five panel members did not agree with the use of the term “religion”. The major argument was that religion was not applicable to all caregivers. The term “spiritual activities” was finally adopted instead. The last item was scored -.07. The negative value indicated that more than half of the panel members did not regard it as relevant. The eight members commented that “Qigong” might not have sound therapeutic values. The focus group clarified and ultimately decided to phrase the term as “mind-body exercise”. No item was deleted finally.

3.1.2.3. DATA COLLECTION

To ensure the validity of the results, independent assessors including qualified psychiatrists, mental health nurses and occupational therapists were trained to use the instruments. They attended a training workshop conducted by the research group. In

order to be qualified to be the administrator, they also needed to go through and pass in a certification process in which their familiarity of the contents of the instruments and their actual performance in the usage were assessed. After obtaining the written consent from the participant, an assessor was randomly selected to administer the instrument and record the results accordingly through a face-to-face interview in a closed room of the centre to ensure privacy. The interview lasted for about 45 to 60 minutes for PRNQ-S-WX and 30 to 45 minutes for PRNQ-C-WX. As for the intra-rater reliability of both of the questionnaires respectively, each of a total of 30 participants who was assessed by an assessor in the first administration was assessed by the same assessor again within one to two weeks afterwards.

3.1.2.4. DATA ANALYSIS

Descriptive and frequency statistics were used to summarize the demographic data of the participants and the results of the surveys of the both questionnaires respectively (mean and SD). Coefficient alpha was adopted to examine the internal consistencies of the overall scale and sub-scales. Intra-rater reliability of the instrument was assessed by two-way mixed intraclass correlation (ICC) coefficient using the scores in the first and second administrations of the scale. Factor analysis was conducted to improve the understanding on the structural validity of the scale. Exploratory factor analysis was performed to explore the interrelationships among the items of the scale. All data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 17.

3.1.2.4.1. EXPLORATORY FACTOR ANALYSIS

Exploratory factor analysis (EFA) is adopted to determine the number of continuous latent variables (factors) necessary to account for the correlations among a set of observed variables (Child, 1990). EFA is useful for developing and validating measurement tools (Lovett et al., 2002). EFA is superior to principal components analysis (PCA) as the latter only serves to reduce data without any regard to the underlying structure caused by the factors (Ford et al., 1986). Costello & Osborne (2005) support the adoption of EFA as it can reveal any factors which make the manifest variables co-vary. During factor extraction, the shared variance of a variable is partitioned from its unique variance and error variance in order to reveal the underlying factor structure. PCA is however unable to discriminate between the shared variance and the unique variance. It is problematic as it is likely to produce inflated values of variance explained by the components when the factors are uncorrelated and the communalities are moderate (Gorsuch, 1997). Such issues do not exist in EFA as it only analyzes shared variance that yields the same solution (all other things being equal) and hence avoids the inflation of the estimates of the variance accounted for. EFA is commonly used to explore the interrelationships among the items of measurement scale. Kaiser-Meyer-Olkin (KMO) measure and Bartlett's test of sphericity are used to determine factor extraction (Hair et al., 2006). The KMO is the measure of sampling adequacy that ranges between 0 and 1, with that closer to 1 being better and .6 being the minimum indicating adequate sampling. Bartlett's test of sphericity is to test the hypothesis that the correlation matrix is an identity matrix, and the value should be < .5 which shows that the variables are

correlated. Both criteria should be met before executing EFA using the data set (Foulger, 2010). Factor with eigen-values over 1 can be extracted along the varimax rotation which represents that a substantial variance explained by that factor (Jolliffe, 1986). A scree plot is then generated and examined. It shows the eigenvalues on the y-axis and the number of factors on the x-axis. The number of factors to be extracted is the number of factors before the plotted line turns sharply right (Brown, 2001). This point is called the point of inflexion which is the intersect of the line summarizing the vertical part of the plot and the line summarizing the horizontal part. This method of factor extraction is reliable in a sample of 200 participants or above (Stevens, 2002). Multicollinearity among the factors is then to be tested (Field, 2009). Multicollinearity exists when two or more of the factors in a regression model are correlated either moderately or highly, which is unwanted in EFA as it undermines the uniqueness of the factors (Grewal et al., 2004). Therefore, identity matrix has to be achieved which indicates that the factors are independent and hence no further reduction of the number of factors is needed. This determines the factor solution. If, for instance, there are eight factors, it will be an eight-factor solution. The total variance can finally be found. There is a proportion of variance in each factor which means how much that factor accounts for the total variance. In other words, the total variance is the sum of the proportions of all of the factors.

3.1.3. RESULTS

3.1.3.1. INTERNAL CONSISTENCIES AND INTRA-RATER RELIABILITY

3.1.3.1.1. PRNQ-S-WX

Coefficient alpha of the total score of PRNQ-S-WX was very good (.90). The internal consistencies of different subscales based on the results from EFA ranged from .90 (Family and Discrimination) to .92 (Social security, Treatment adherence, Psychosocial care, and Community rehabilitation). The ICC coefficient was .99 for the total scale. The mean scores, standard deviation, and coefficient alpha are summarized in Table 3.

Table 3
Mean scores, standard deviation, ICC, coefficient alpha of the subscales of PRNQ-S-WX

Name of subscales (Part I of PRNQ-S-WX)	Number of items	*n* = 250			
		M	SD	ICC (*n* = 30)	Alpha
1. Occupation	13	3.77	1.25	.99*	.91
2. Behavior and impulse control	6	2.75	1.31	.97*	.91
3. Family and Discrimination	10	3.76	1.02	.98*	.90
4. Social welfare and Housing	8	3.08	1.20	.98*	.91
5. Self-care	4	3.34	1.29	.98*	.91
6. Leisure	3	2.82	1.39	.98*	.91
7. Stress management	4	4.07	.86	.91*	.91
8. Medical services and treatment	4	3.53	1.12	.97*	.91
9. Social security	3	4.43	.87	.95*	.92
10. Social and intimate relationship	5	2.96	1.26	.98*	.91
11. Mental health knowledge	4	4.20	.78	.96*	.91
12. Treatment adherence	3	4.28	.83	.79*	.92
13. Symptom management	3	4.10	.97	.96*	.91
14.Psychosocial care	1	4.42	1.02	.81*	.92
15.Community rehabilitation	1	4.28	1.02	.84*	.92
16.Emotion management	1	4.52	.82	.84*	.91
17. Education	2	2.81	1.46	.97*	.91
Total	75	3.71	.68	.99*	.90

3.1.3.1.2. PRNQ-C-WX

Coefficient alpha of the total score of PRNQ-C-WX was very good (.89). The internal consistencies of different subscales based on the results from EFA ranged from .86 (Leisure and Social life) to .91 (Stress management). The ICC coefficient was .99 for the total scale. The mean scores, standard deviation, and coefficient alpha are summarized in Table 4.

Table 4
Mean scores, standard deviation, ICC, coefficient alpha of the subscales of PRNQ-C-WX

Name of subscales (Part I of PRNQ-C-WX)	Number of items	*n* = 200			
		M	SD	ICC (*n* = 30)	Alpha
1. Leisure & Social life	7	3.05	1.10	.99*	.86
2. Stress management	8	4.44	.63	.82*	.91
3. Caring skills	7	4.16	.69	.98*	.87
4. Social support	6	4.04	.87	.99*	.87
5. Security	8	3.93	.84	.97*	.87
6. Burden reduction & Financial support	7	3.98	.91	.99*	.88
7. Work & Responsibility	5	3.74	.96	.99*	.87
8. Accommodation	2	2.68	1.15	.98*	.89
Total	50	3.76	.64	.99*	.89

*$p < 0.05$
Response choices for PRNQ-C-WX: 1 = "never important"; 2 = "seldom important";3= "sometimes important"; 4 = "usually important"; 5 = "always important"

3.1.3.2. EFA

3.1.3.2.1. PRNQ-S-WX

EFA showed that the 75 items of the first section of PRNQ-S-WX were categorized into 17 factors. The KMO measure was used to determine factor extraction. A value greater than .8 indicated sampling adequacy and suggested that EFA could be proceeded using the data set (Foulger, 2010). The KMO value in this study was .91 which justified the execution of EFA. The factor scores indicated that the scores of each of the factors could be used to test for multicollinearity (Field, 2009). In this study, the identity matrix was achieved which indicated that the 17 factors were independent and hence no further reduction of the number of factors was needed. This seventeen-factor solution accounted for 81.3% of the total variance. All of the factors were found to have good and simple structure. The item allocation was mainly based on the significant loadings from the EFA results and the nature of content. None of the items had low factor loadings in EFA. All of the items could be meaningfully interpreted in the assigned factors. The factorial structures of PRNQ-S-WX and PRNQ-S-HK and their corresponding factor loadings are presented in Table 5.

Table 5

Factor structures and factor loadings of PRNQ-S-HK and PRNQ-S-WX

HK Factors	% of variance	Factor loadings	Items	Factor loadings	% of variance	WX Factors
1. Occupation (13 items)	8.6%	.77	9. Strengthen interview skills	.81	16.2%	1. Occupation (13 items)
		.76	2. Increase employment opportunities	.85		
		.74	4. Improve relations with superiors	.88		
		.73	1. Enhance motivation to work	.77		
		.66	8. Provide job training opportunities	.86		
		.64	3. Improve relations with co-workers	.87		
		.61	5. Enhance working skills	.90		
		.61	7. Provide ongoing vocational support	.88		
		.54	11. Improve promotion prospect	.79		
		.54	10. Allow staff take leaves for psychiatric follow-up	.85		
		.53	6. Enhance job tenure	.87		
		.50	12. Obtain a reasonable salary	.86		
		.49	13. Increase the varieties of work types	.84		
2. Social welfare and security (7 items)	6.6%	.78	55. Provide sufficient transport expenses	.31	5.8%	4. Social welfare and Housing (4 of 8 items)
		.74	54. Provide sufficient food	.47		
		.70	56. Provide sufficient entertainment expenses	.42		
		.66	57. Provide sufficient medical expenses	.42		
		.64	64. Provide sufficient amount of Social Security Allowance	.87	3.9%	9. Social security (3 items)
		.57	66. Increase channels for help seeking	.82		
		.45	65. Provide sufficient assistance in the community	.91		
3. Medical services (6 items)	5.3%	.72	23. Provide sufficient mental health professionals for follow-up	.50	5.1%	5. Self-care (1 of 4 items)
		.58	24. Increase resources for community rehabilitation	.81	1.8%	15. Community rehabilitation (1 item)
		.44	25. Improve the understanding of patients' psychological needs	.78	2.6%	14. Psychosocial care (1 item)
		.42	19. Provide sufficient channels to obtain relevant information	.43	3.4%	11. Mental health knowledge (1 of 4 items)
		.67	26. Avoid frequent change of medical staff to maintain a stable relationship	.66	4.0%	8. Medical services

		.37	29. Increase the duration of psychiatric consultation	.58		and treatment (2 of 4 items)
4. Family (6 items)	5.1%	.71	40. Able to get tangible support from the family	.66	8.0%	3. Family and Discrimination (6 of 10 items)
		.52	38. Avoid over-expectation from the family	.52		
		.43	41. Acquire sufficient knowledge on birth and family planning	.30		
		.37	39. Able to get emotional support from the family	.57		
		.35	42. Increase family's understanding on mental illness	.54		
		.33	37. Improve the relationship with family	.55		
5. Social and intimate relationship (5 items)	5.0%	.79	33. Expand social network	.69	3.9%	10. Social and intimate relationship (5 items)
		.73	34. Enhance motivation in social life	.68		
		.70	32. Improve social skills	.66		
		.56	35. Improve skills getting along with other sex	.48		
		.43	36. Gain proper sex knowledge	.40		
6. Behavior and impulse control (5 items)	4.8%	.79	74. Reduce aggressive behavior	.86	8.2%	2. Behavior and impulse control (5 of 6 items)
		.73	73. Reduce suicidal behavior	.86		
		.70	75. Reduce alcoholic behavior	.84		
		.56	67. Avoid over spending	.40		
		.43	68. Enhance ability of budget management	.35		
7. Symptom management (5 items)	4.6%	.79	17. Increase ways of handling symptoms	.57	3.0%	13. Symptom management (2 of 3 items)
		.70	14. Alleviate positive and negative symptoms	.71		
		.72	15. Maintain stable emotion	.37	1.7%	16. Emotion management (1 item)
		.38	18. Enhance knowledge on mental illnesses and medication	.46	3.4%	11. Mental health knowledge (1 of 4 items)
		.36	47. Attend psychiatric appointment timely			
8. Right for treatment (5 items)	3.4%	.77	27. Being prescribed of the appropriate medication	.66	3.4%	11. Mental health knowledge (2 of 4 items)
		.73	28. Reduce the side-effect of medication	.70		
		.55	30. Reduce the waiting time of for first psychiatric consultation	.65	4.0%	8. Medical services and treatment (2 of 4 items)
		.50	31. Improve patients' right for choosing their types of treatment	.63		
		.34	49. Participate actively in psychiatric treatment			
9. Discrimination (4 items)	4.5%	.68	62. Reduce being discriminated by the community	.80	8.0%	3. Family and Discrimination
		.59	61. Reduce being discriminated by the family	.65		

		.47	63. Reduce self-discrimination and the sense of inferiority	.65		(4 of 10 items)
		.45	60. Reduce the chance of being excluded	.71		
10. Housing (4 items)	4.2%	.78	51. Improve living space	.78	5.8%	4. Social welfare and Housing (4 of 8 items)
		.71	53. Provide sufficient choices of housing	.78		
		.59	52. Avoid too long distance from residence to service network	.52		
		.58	50. Provide sufficient transitional housing arrangement	.76		
11. Self-care (4 items)	4.4%	.82	21. Improve ability of household management	.69	5.1%	5. Self-care (3 of 4 items)
		.71	20. Improve self-care skills	.66		
		.68	22. Improve ability of managing own property	.65	3.0%	
		.45	16. Improve personal hygiene	.75		13. Symptom management (1 of 3 items)
12. Stress management (3 items)	3.1%	.73	69. Reduce anxiety	.77	4.3%	7. Stress management (3 of 4 items)
		.61	70. Reduce pressure of everyday life	.79		
		.59	71. Improve stress management skills	.82		
13. Leisure (3 items)	2.9%	.68	46. Increase interest in leisure	.69	4.8%	6. Leisure (3 items)
		.68	44. Provide sufficient leisure opportunities	.71		
		.67	45. Develop appropriate leisure arrangement	.72		
14. Education (2 items)	2.6%	.76	59. Provide sufficient opportunities for further studies	.40	1.5%	17. Education (2 items)
		.65	58. Provide sufficient opportunities for basic education	.46		
15. Care for children (1 item)	1.9%	.66	43. Improve the skills of taking care of children	.45	8.2%	2. Behavior and impulse control (1 of 6 items)
16. Treatment adherence (1 items)	1.8%	.59	48. Improve the drug adherence			
17. Lifestyle (1 item)	1.8%	.68	72. Develop a structural daily life	.47	4.3%	7. Stress management (1 of 4 items)
			47. Attend psychiatric appointment timely	.71	3.1%	12. Treatment compliance (3 items)
			48. Improve the drug compliance	.74		
			49. Participate actively in psychiatric treatment	.79		

3.1.3.2.2. PRNQ-C-WX

EFA showed that the 50 items of the first section of PRNQ-C-WX were categorized into eight factors. Factor extraction was determined by the KMO measure. The KMO value in this study was .87 which justified that the EFA could be executed. The identity matrix was achieved in this study which indicated that the eight factors were independent and hence no further reduction of the number of factors was needed. This eight-factor solution accounted for 65.0% of the total variance. All of the factors were found to have good and simple structure. The item allocation was mainly based on the significant loadings from the EFA results and the nature of content. None of the items had low factor loadings in EFA. All of the items could be meaningfully interpreted in the assigned factors. The factorial structures of PRNQ-C-WX and PRNQ-C-HK and their corresponding factor loadings are presented in Table 6.

Table 6

Factor structures and factor loadings of PRNQ-C-HK and PRNQ-C-WX

HK Factors	% of variance	Factor loadings	Items	Factor loadings	% of variance	WX Factors
1. Stress management (9 items)	9.8	.80	42. Reduce the worries over the patient‘s future	.76	10.9	2. Stress management (7 of 8 items)
		.74	43. Reduce the worries over the patient‘s safety	.74		
		.70	37. Reduce the pressure on working and taking care of the patient at the same time	.72		
		.64	36. Reduce the apprehension of the change of condition of the patient	.81		
		.63	41. Obtain peer support and encouragement	.70		
		.56	38. Reduce the worries over unexpected problem of the patient	.79		
		.56	39. Reduce the psychological burden due to the lack of understanding of the patient‘s condition	.74		
		.50	47. Reduce the difficulty in caretaking brought by the daily habit of the patient	.64	5.9	7. Work & Responsibility (2 of 5 items)
		.43	44. Make time to take care of the patient’s daily life	.60		
			40. Reduce the frustration brought by the fluctuation of the patient‘s condition	.70	10.9	2. Stress management (1 of 8 items)
2. Security & Caring skills (12 items)	8.5	.73	26. Increase understanding of mental illness and accept part of the behavior of the patient	.37	7.8	5. Security (5 of 8 items)
		.66	27. Strengthen communication with the patient and build a mutual trust relation	.28		

		.65	29. Change the conception that the caregiver is responsible for the illness of the patient	.68		
		.45	22. Improve relation with other family members	.83		
		.35	23. Increase the acceptance of the patient by the family	.85		
		.66	30. Increase knowledge of mental illness	.66	8.4	3. Caring skills (7 items)
		.68	25. Enhance communication skills with the patient	.48		
		.65	32. Increase channels of obtaining information	.66		
		.55	31. Provide professionals on answering enquiries	.52		
		.51	28. Provide knowledge on differentiating the patient's personalities from the symptoms	.69		
		.51	46. Understand the proper attitude of care taking	.44		
		.48	45. Strengthen caring skills	.46		
3. Leisure & Social life (7 items)	8.2	.86	48. Increase the time for entertainment	.75	11.4	1. Leisure & Social life (7 items)
		.80	50. Increase the motivation of entertainment	.80		
		.73	49. Increase the type of entertainment	.81		
		.66	20. Expand the friend circle in which one is the centre of the circle	.80		
		.51	21. Increase support and understanding from friends and thus expand one's social network	.77		
		.49	18. Increase time for social life	.71		

		.43	19. Reduce self isolation and social withdrawal	.75		
4. Burden reduction (5 items)	6.9	.78	11. Reduce the burden of urging patient to take medication	.73	10.9	6. Burden reduction & Financial support (4 of 7 items)
		.77	12. Reduce the worries on the patient‘s taking of medication	.75		
		.68	13. Reduce the burden brought by the side effect of medication of the patient	.46		
		.58	24. Reduce the effect on the relation resulted from urging the patient to take medication	.72		
		.49	40. Reduce the frustration brought by the fluctuation of the patient’s condition			
5. Social support (6 items)	5.8	.76	8. Provide support catered for the needs of caregivers	.67	8.3	4. Social support (6 items)
		.73	10. Provide the awareness of support	.70		
		.61	9. Provide information on identifying the kind of support required	.68		
		.57	6. Increase channels of seeking help	.62		
		.42	7. Provide psychological counseling service	.64		
		.38	14. Increase support by other mental health professionals apart from doctors	.30		
6. Financial support (3 items)	4.9	.50	15. Reduce the additional financial reserve for the patient	.55	6.9	6. Burden reduction & Financial support (3 of 7 items)
		.45	16. Increase the right of managing the Comprehensive Social Security Assistance (CSSA) allowance of the patients	.40		
		.16	17. Provide sufficient money for the expense of new medication	.58		

7. Work & Accommodation (4 items)	4.5	.79	3. Able to handle one‘s work and take care of the patient at the same time	.43	5.9	7. Work & Responsibility (2 of 5 items)
		.39	1. Reduce the influence on one‘s work performance because of the phone calls made by the patient	.48		
		.56	5. Increase living space	.98	4.3	8. Accommodation (2 items)
		.36	4. Reduce the waiting time for halfway house	.97		
8. Discrimination reduction (4 items)	3.8	.76	2. Reduce discrimination against family members of mental illness patient	.41	5.9	7. Work & Responsibility (1 of 5 items)
		.58	33. Reduce discrimination by the society	.41	7.8	5. Security (3 of 8 items)
		.57	35. Reduce the deprivation for being family member of mental illness patient	.32		
		.46	34. Reduce self-discrimination	.45		

3.1.3.3. COMPARISON OF THE STRUCTURES OF THE HONG KONG VERSIONS

3.1.3.3.1. PRNQ-S-HK AND PRNQ-S-WX

The structures of PRNQ-S-WX and PRNQ-S-HK are similar, both consisting of 17 factors. The resulting factors indicated that there was good alignment of the constructs between the two questionnaires. The factors in PRNQ-S-HK included “Occupation”, “Social welfare and security”, “Medical services”, “Family”, “Social and intimate relationship”, “Behavior and impulse control”, “Symptom management”, “Right for treatment”, “Discrimination”, “Housing”, “Self-care”, “Stress management”, “Leisure”, “Education”, “Care for children”, “Treatment adherence” and “Lifestyle”. The factors in PRNQ-S-WX were “Occupation”, “Behavior and impulse control”, “Family and Discrimination”, “Social welfare and Housing”, “Self-care”, “Leisure”, “Stress management”, “Medical services and treatment”, “Social security”, “Social and intimate relationship”, “Mental health knowledge”, “Treatment compliance”, “Symptom management”, “Psychosocial care”, “Community rehabilitation”, “Emotion management” and “Education”. There were nine factors (“Occupation”, “Behavior and impulse control”, “Family and Discrimination”, “Self-care”, “Leisure”, “Stress management”, “Social and intimate relationship”, “Symptom management”, and “Education”) which had the common names in both questionnaires. The rest of the factors in one questionnaire were mainly the combination of the factors in the other. For instance, “Family and discrimination” stood as one single factor in PRNQ-S-WX but “Family” and “Discrimination” were two separate factors in PRNQ-S-HK. At the item level, all of the items were able to be meaningfully interpreted in the assigned factors according to the factor loadings and the nature of content. The item allocation of PRNQ-S-WX was

overall consistent with that of PRNQ-S-HK. For example, the items in the four factors, namely, “Occupation”, “Leisure”, “Social and intimate relationship” and “Education”, in PRNQ-S-WX were identical in the same factors respectively in PRNQ-S-HK. Besides, the items in other factors in PRNQ-S-WX only slightly differed from those in PRNQ-S-HK. For instance, the four items in the factor “Stress management” in PRNQ-S-WX contained all of the three items (“Reduce anxiety”, Reduce pressure of everyday life”, and “Improve stress management skills”) in the same named factor in PRNQ-S-HK. As for the percentage of the total variance explained, the factor ‘‘Occupation’’ had the greatest contribution to the corresponding proportion of the total variance in both questionnaires (8.6 % out of 70.7 % in PRNQ-S-HK and 16.2 % out of 81.3 % in PRNQ-S-WX). However, the lowest significant contribution was not the same. They were the factor “Lifestyle” (1.8 %) in PRNQ-S-HK and the factor “Education” (1.5 %) in PRNQ-S-WX.

3.1.3.3.2. PRNQ-C-HK AND PRNQ-C-WX

The PRNQ-C-WX shared similar structure with PRNQ-C-HK, with eight factors both. The constructs based on the resulting factors demonstrated good alignment between the two questionnaires. The factors in the Hong Kong version included “Stress management”, “Security and Caring skills”, “Leisure and Social life”, “Burden reduction”, “Social support”, “Financial support”, “Work and Accommodation” and “Discrimination reduction”. Those in the Wuxi version were “Leisure and Social life”, “Stress management”, “Caring skills”, “Social support”, “Security”, “Burden reduction

and Financial support", "Work and Responsibility" and "Accommodation". Three factors ("Leisure and Social life", "Stress management" and "Social support") had the same names in both versions. The remaining factors in one version were mainly the combination of those in the other. For instance, "Security and Caring skills" existed as one single factor in PRNQ-C-HK but "Security" and "Caring skills" stood as two separate factors in PRNQ-C-WX. On the other hand, "Burden reduction" and "Financial support" were two separate factors in the Hong Kong version but were combined into one single factor in the Wuxi version. At the item level, all of the items could be meaningfully interpreted in the assigned factors according to the factor loadings and the nature of content. The item allocation of PRNQ-C-WX was fairly consistent with that of PRNQ-C-HK. For instance, the items in the two factors ''Leisure and Social life'' and ''Social support'' in the Wuxi version were identical in the same factors respectively in the Hong Kong version. Moreover, seven out of the eight items of the factor "Stress management" in the Wuxi version were the same as those out of the nine items of the same named factor in the Hong Kong one. As for the percentage of the total variance explained, ''Stress Management'' had the most significant contribution to the corresponding proportion of the total variance in both questionnaires (9.8 % out of 64.2 % in PRNQ-C-HK and 10.9 % out of 63.8 % in PRNQ-C-WX). The smallest contribution was however different. They were the factor "Discrimination reduction" (3.8 %) in the Hong Kong version but the factor "Accommodation" (4.3 %) in the Wuxi one.

3.1.4. DISCUSSION

3.1.4.1. PRNQ-S-WX

With reference to the shared historical and cultural roots between Hong Kong and Wuxi, and yet the unique social and service delivery modes in the mainland, PRNQ-S-WX has been adapted from PRNQ-S-HK using expert panel method and EFA. The results indicated that all of the 17 factors in the Wuix version had a good and simple structure as in the HK version (with the same number of factors), with all of the items having been meaningfully interpreted in the assigned factors. This showed that PRNQ-S-WX is structurally valid. Besides, its excellent internal consistency indicated that its items in the subscales measure the same construct. These findings have collectively supported that the PRNQ-S-WX has contributed to developing measurement tools for assessing the needs of persons with schizophrenia. This tool is superior to the current three related instruments including CAN, MRC-NCA and SLICLS as discussed in Chapter Two. There is a further opportunity for CAN and SLICLS to supplement PRNQ-S-WX as they have been culturally validated in Chinese population (Au et al., 2005; Yeh et al., 2006) and so an even more comprehensive and deeper investigation of the needs of people with schizophrenia and the corresponding intervention outcomes in Chinese societies can be made possible.

By EFA, the contribution of the factor “Occupation” to the total variance in PRNQ-S-WX was the most significant (16.2% out of 81.3%). It was the same in the Hong Kong version. This reflected that the persons with schizophrenia in the Chinese societies cared much about work. It is in line with the literature that return-to-work is a

significant determinant of recovery and hence a crucial goal of interventions for people with mental illness (Tsang & Chen, 2007). There are urgent needs for the persons with schizophrenia to seek and sustain a job. As found in the category on employment status in PRNQ-S-WX, most of the consumers worked in family business or simply participated in some light farming work around their living place. As for the open employment, some industries in Wuxi allow the employees with mental illness to go on receiving salary and benefits without actually resuming the duties. Nonetheless, the contemporary philosophy and practice of vocational rehabilitation is to enable the persons with schizophrenia to resume their worker role in the open job market by optimizing their strengths and overcoming the barriers (Tse et al., 2015). More resources should therefore be invested to support research on the return-to-work predictors and the advancement of intervention modalities of vocational rehabilitation such as the ISE. The least significantly contributed factor to the total variance on the other hand was “Education” (1.5% out of 81.3%). It is interesting to note that while correlation usually exists between education and occupation (Pages & Stampini, 2007), these two factors varied much in their corresponding contributions to the total variance (“Occupation” contributed most greatly). Besides, it echoes with the findings in a study (Tsang, 2011) that the persons with schizophrenia and their caregivers had different concerns in education. The caregivers in particular females were found to care much about the education aspect of their family members with schizophrenia. It is not surprising as women are obligated to take up the responsibilities for nurturing children through arranging appropriate schooling (Malhotra and Sachdeva 2005). The phenomenon that the persons with schizophrenia did not seem to concern much about studies could be explained by the facts that their golden period for receiving

formal education had gone which made them hard to catch up with the progression of their study paths. It is worth further investigating for verification.

3.1.4.2. PRNQ-C-WX

Using expert panel method and EFA, PRNQ-C-WX has been adapted from PRNQ-C-HK with reference to the common historical and cultural origin between Hong Kong and Wuxi but the specific modes of social and service delivery in the mainland. The results revealed that all of the eight factors in the Wuxi version had a good and simple structure as in the HK version (with identical number of factors) and all of its items could be meaningfully interpreted in the assigned factors. This indicated that this version is structurally valid. Moreover, its items in the subscales measure the same construct as reflected by the excellent internal consistency. The contribution of PRNQ-C-WX to the development of assessment tools for measuring the needs of caregivers of persons with schizophrenia has been clearly shown. This scale is superior to the current three similar assessment tools including NFCAS, RCNS and CNA-S as discussed in Chapter Two. These three instruments can however supplement PRNQ-C-WX to widen the perspectives in understanding the caregivers in both problem-level and need-level.

By EFA, the contributions of the factors “Leisure and Social life” and “Stress Management” to the total variance in PRNQ-C-WX were found to be significant (11.4% and 10.9% respectively out of 63.8%). The same was noted in the PRNQ-C-HK. It reflected that the life of caregivers of persons with schizophrenia in Chinese societies was very stressful. It is thus reasonable to suggest that stress management should be included

in the clinical services. Besides, the findings also revealed that the caregivers desired more leisure and social activities. They could not have sufficient leisure and social opportunities due to the time constraints in the caring process. It is a critical determinant of immense burdens (Lauber et al., 2003). It will be problematic if this need cannot be properly met as the stress the caregivers cannot be relieved. Unfortunately, the provision of the related services remains limited (Yusuf et al., 2009). More efforts should be paid to explore the feasibility of increasing the provision. In fact, the family caregivers in mainland China cannot receive enough support (Yin et al., 2014). There are laws and regulations on family obligations in caring the relatives with mental illness in the Chinese government which make the general public think that the family has to take full and sole responsibility in the caring process (Leung, 1997). Nevertheless, the support from the healthcare system to the family members remains scarce (Ran et al. 2005). This makes the caring process stressful and overwhelming. Their quality of life is undermined by the failure of the fulfillment of the needs which in turn compromises the quality of care (World Federation of Mental Health 2010). PRNQ-C-WX can enable a more thorough and systematic understanding of the needs of the caregivers and thus tailor needs-driven services to satisfy their needs and hence enhance their life quality.

3.1.5. IMPLICATIONS OF FINDINGS

The findings of these two validation studies have generated some insight on the perceived needs of people with schizophrenia and their caregivers in the rehabilitation process. Despite a number of studies examining the quality of life of persons with

schizophrenia (e.g., Awad & Voruganti, 1999; Katshnig, 2000; Landeen et al., 2000) and exploring the burden of the caregivers (e.g., Martens & Addington, 2001; Caqueo-Urı´zar & Gutie´rrez-Maldonado, 2006), the underlying reason for poor quality of life and immense burden of both stakeholders remains unknown. The findings in this phase of study have filled the gap in the literature by having developed and validated two instruments to assess scientifically the importance of the perceived rehabilitation needs of the two major stakeholders in Wuxi. These tools have become the first of its kinds in mainland China. They can be adopted in all other places in the mainland upon some minor adaptations. With further research, broader and deeper understanding on the rehabilitation needs can be made possible. The research may include quantitative studies comparing the needs between the urban and rural areas in Wuxi, or between Wuxi and other region(s), and advanced statistical analyses such as binary logistic regression to investigate the factor(s) predicting the participants in the urban or rural regions. It would then sharpen the strategies for enhancing the quality of life of the two stakeholders by tailoring the interventions to fulfill their needs accordingly. It would also lay a solid foundation for formulating evidence-based mental health policies to more precisely develop the mental health services and practices in mainland China.

3.1.6. LIMITATIONS

There are some limitations in these two validation studies. As a thumb rule, five participants are needed per item in EFA. Hence, there should have been at least 375 participants for the 75-item PRNQ-S-WX, and 250 participants for the 50-item PRNQ-C-

WX. However, the numbers of participants of PRNQ-S-WX and PRNQ-S-WX in the EFA of these two studies were respectively 250 and 200 only. Besides, convenience sampling from a single site was used to recruit all of the participants. The relatively small sample sizes and the non-random sampling method might have affected the external validity of the studies. Nevertheless, PRNQ-S-WX and PRNQ-C-WX were adapted from the corresponding versions having been validated in Hong Kong and all of the items were extracted scientifically through qualitative approach and finally categorized by EFA meaningfully. To enhance the generalizability, it is worth conducting further validation studies with larger sample size from various sites through random sampling. Lastly, to our knowledge, the theoretical framework of the rehabilitation needs has not ever been scientifically conceptualized. Confirmatory factor analysis (CFA) should hence be conducted to verify the constructs of the needs. CFA is deployed to generate a more explicit framework for confirming prior understanding about the factors found in EFA, and hence facilitates theory-testing, theory-comparison or theory-development in a measurement context (Steiger, 2013). It is achieved by enabling researchers to evaluate the degree of consistency of their measurement hypotheses with the respondents' data, and hence modify those hypotheses to be more consistent with the actual structure of the responses to the scale (Tavakol et al., 2011).

3.2. PHASE TWO: QUALITATIVE STUDY

3.2.1. INTRODUCTION

As discussed in Chapter Two, the severity and chronicity of schizophrenia and its significant consumption of mental health care resources have made it a major cause of disability worldwide (World Health Organization, 2008) and a tremendous global burden of health finances (Bhugra, 2005). Over half of the persons with schizophrenia are not provided with appropriate care. The conditions are even more alarming in developing countries where as high as 90% of the consumers have not had their mental illness properly treated (World Health Organization, 2012). This chronic illness affects not only the consumers but also the family caregivers who experience heavy practical and emotional burden in the caring process including sacrifice of time and high stress (Lowyck et al., 2004). This may then compromise their quality of life and hence the quality of care (World Federation for Mental Health, 2010). Because of the strong cultural value on familial obligations, family caregivers in Chinese societies are highly expected to take a main role in caring the family member with mental illness in different aspects such as medication adherence, and employment, as compared to the western countries where the healthcare system bears the major caring responsibility (Yip, 2005). Nevertheless, the support to the caregivers is insufficient (Zhang et al., 2014b). In fact, the medical and rehabilitation care in China fails to benefit from the economic growth that its healthcare system has not been improved significantly (Minister of Health, 2005) and its healthcare resources have not been allocated effectively (Hew, 2006). While 70% of the total population is living in the rural regions, only 20% of the total health expenditures are however distributed there (Shi & Gong, 2005). As in 2011, for every

100,000 people in Nanjing there were only 0.06 mental hospital, and 13.72 and 1.00 psychiatric beds in mental hospital and general hospital respectively. These rates were much lower than the international standards (World Health organization, 2012). Such serious disproportionate allocation of resources can be reflected, for example, by the skewed availability of the expensive psychiatric treatment services in the urban regions (Philips, 2000). As a result, many people in either the urban or the rural areas fail to afford the necessary interventions including medication and hospitalization (IBM, 2006). Although health insurance systems exist, there is a disparity in the insurance schemes that the insurance plans are more available in the urban areas than the rural areas (Liu et al., 2011). Even with more choices of the plans in the well-developed urban regions, the insured population however remains limited. For example, only about 10% of the people with mental illness in Beijing can have their inpatient treatment covered by insurance (Wang et al., 2014). In terms of the coverage in the scope and the proportion of reimbursement, there has been a gradual improvement but large variations still exist within the mainland depending on the various insurance schemes and the regions. Compared with the plans provided by the local governments in the less developed areas, those contributed by employers in the wealthier cities generally have higher premiums and hence better coverage such as inclusion of both inpatient and outpatient services and a higher proportion in drug reimbursement (Sussmuth-Dyckerhoff & Wang, 2010). In views of the above situations, it is of urgent needs to formulate precise mental health policies to devise effective strategies to address such alarming issues (Jenkins, 2001). The most crucial goal of mental health policies is to develop directions for tackling specific mental health situations according to the priorities (Government of Western Australia,

2004). It is thus necessary to incorporate the views of the major stakeholders including the consumers and their caregivers into the planning stage (World Health Organization, 2004). Otherwise, no policy will work well (Jenkins, 2007). In fact, failure to fulfill the needs of the stakeholders results in poor quality of life (Hansson et al., 2003). Health policy makers and healthcare providers thus have to understand the various needs of the consumers and their caregivers towards the medical and rehabilitation interventions, and tailor the interventions to satisfy their needs accordingly (Wang et al., 2012). This process can be facilitated by using a scientific "needs-led" approach (Harvey & Fielding, 2003). It is a response to the paradigm shift of mental health service delivery from service-driven to needs-driven (Lightfoot, 1995) and it has become the philosophy in the decision-making process in health policy formulation (Evans et al., 2000).

Information on the rehabilitation needs of persons with schizophrenia and their caregivers is extremely limited in China. The successful validation of PRNQ-S-WX and PRNQ-C-WX in Phase One of this study has partially filled the gap. In order to enrich the understanding of the views of the consumers and caregivers towards the psychiatric rehabilitation policy and services in the urban and rural areas of Wuxi, the qualitative study in this phase was conducted through individual semi-structured interviews. Semi-structured interview is a two-way dialogue which is effective for promoting in-depth discussion as it facilitates the interviewee to freely express his own thoughts and feelings (Offredy& Vickers, 2010). It is particularly useful for exploring specific situations as well as supplementing and validating information (as a means of triangulation) in questionnaire studies and hence gaining insight into issues not immediately perceptible yet of concerns of the interviewees (Laforest & Bouchard, 2009). In fact, different

stakeholders usually have different views (Tsang et al., 2013). Exploring such differences can lead to a better understanding on the complexity of issues from various angles which can in turn help to formulate more precise solutions. Thus, the views between the two stakeholder groups would be compared in this study.

This qualitative study adopted semi-structured individual face-to-face interviews which aimed to explore and compare the perception of the persons with schizophrenia and their caregivers in the urban and rural areas of Wuxi towards the adequacy and quality of the current psychiatric rehabilitation services. It would serve as triangulation to the quantitative survey in the third and last phase using the two standardized measurement tools (PRNQ-S-WX and PRNQ-C-WX) validated in the first phase. By supplementing and verifying the findings with each other, the understanding on the two stakeholders' awareness and evaluation on the psychiatric rehabilitation policies and services in Wuxi will be more comprehensive and in-depth. This would probably shed light on the ways to sharpen the corresponding strategies to satisfy their needs.

3.2.2. METHOD

3.2.2.1. PARTICIPANTS

Sixteen individual face-to-face semi-structured interviews were conducted with four interviewees for each of the four types of participants (i.e., four urban consumers with schizophrenia, four urban caregivers, four rural consumers with schizophrenia, and four rural caregivers). They were recruited from the Wuxi Mental Health Centre by convenience sampling when they went there for psychiatric appointment. In order to

collect views from both men and women, two males and two females with schizophrenia were recruited from both the urban and rural areas respectively. Likewise, two male caregivers and two female caregivers were recruited from both areas respectively. The persons with schizophrenia were those who had been diagnosed with the illness by the case psychiatrist for at least one year based on the criteria of DSM-IV. They were symptomatically stable, aged 18 or above, and fluent in Putonghua. The caregivers were those who had provided the care for at least one year. They were aged between 18 and 60, and fluent in Putonghua. Anyone failing to understand and express clearly was excluded. The demographic information of the four types of interviewees is summarized in Table 7.

Table 7

Demographic information of the respondents

Respondents	Regions	Gender		Age		Duration of illness (Years)	Duration of caring (Years)
		Male *n* = 8	Female *n* = 8	Range	Mean	Mean	Mean
Persons with schizophrenia	Urban	2	2	40 - 56	48.0	12.3	
	Rural	2	2	36 - 58	45.5	6.8	
Caregivers	Urban	2	2	53 - 83	65.8		12.3
	Rural	2	2	35 - 59	49.0		4.8

3.2.2.2. DATA COLLECTION

The interviews were done by me as an occupational therapist with more than 10 years of experience in psychiatric rehabilitation and having trained by my supervisor on the skills essential to conducting the interviews. Four corresponding interview guides (one per each type of participants) were developed to direct the flow of the interview and ensure that the topics and issues to be explored were adequately covered using semi-structured format. Prior consent was obtained from each participant before the interview. Each interview for the consumers and the caregivers lasting about 25 to 45 minutes and 40 to 60 minutes respectively was conducted in a closed room of the mental health centre to ensure privacy. Five open-ended questions were developed with reference to the Articles of Chapter IV (Rehabilitation of mental disorders) of the China's New Mental Health Law. This Law has been the first of its kind in mainland China adopted since 2012. In order to ensure that the questions were appropriately asked by the interviewers and easily understood by the interviewees, the question set was pilot-tested on the relevancy and the succinctness of wordings by three mental health professionals in Wuxi (i.e., one psychiatrist from a hospital, one psychiatrist from a community setting, and one occupational therapist with experience of inpatient and community services) and two mental health professionals in Hong Kong (i.e., one occupational therapist with experience of inpatient and community services, and one social worker from a community setting). The questions were revised according to their comments. The finalized five questions when translated to English were (1) "What kinds of rehabilitation skills training does your community rehabilitation setting provide? Are they enough?"; (2) "What kinds of illness-related services does your community provide? Are they

enough?"; (3) "What kinds of methods does your community use to help you solve your financial hardship? How about the effectiveness?"; (4) "Do you think persons with schizophrenia have job opportunities nowadays? Are there any difficulties?"; and (5) "What kinds of assistance does your community rehabilitation setting provide to caregivers to help persons with schizophrenia recover? Are they enough?". The whole interview was conducted in Putonghua, and audio-recorded, with additional observation notes taken by the interviewer.

3.2.2.3. DATA ANALYSIS

Under supervision, two independent coders developed a codebook based on the 16 interview transcripts using an inductive process including coding, identifying relevant variables, categorizing concepts, and developing possible theoretical themes. Similar responses were organized into themes and categories according to the conceptual proximity and uniqueness. With every pair of the interview transcripts, the coders rated if the identified codes were discussed in response to each interview question. The coders addressed the major discrepancies during coding through thorough discussion. Revisions to the codebook were continued. This process repeated as more transcripts were analyzed with coding items added, revised or deleted until the content of the codebook was saturated and finalized. The finalized codebook was then utilized to analyze each of the interview transcripts again. Satisfactory inter-rater concordance rate of 92.89% was reached. As the native language, Chinese was used in coding each transcript. The interviewees' responses were summarized using qualitative approach. Selected quotes

appeared in the section of results were translated from Chinese to English by qualified translators.

3.2.3. RESULTS

Various issues of the current psychiatric rehabilitation in mainland China were revealed. There were similarities and differences on the views of the persons with schizophrenia (consumers) and their caregivers in both the urban and rural areas.

3.2.3.1. SIMILARITIES BETWEEN CONSUMERS AND CAREGIVERS IN BOTH AREAS

In both areas, both the consumers and their caregivers on one hand expressed that their needs were not satisfied by the rehabilitation interventions and community care they received, and they on the other hand generally did not have good understanding of the concepts of rehabilitation and the role and importance of community care. They expressed that discrimination against people with mental illness was the major external factor hindering open employment. The scarcity of support to caregivers for facilitating consumers' recovery was also noted.

3.2.3.1.1. FAILURE TO SATISFY NEEDS OF REHABILITATION SERVICES

No groups in either area were found to be satisfied with the needs of receiving rehabilitation services. The rural consumers got no rehabilitation service. There were only one caregiver in the rural areas, and only two consumers and one caregiver in the urban areas obtained some brief rehabilitation service. A rural caregiver expressed:

"I don't know if there is any rehabilitation service in the community as I have not ever contacted the community." (RC3)

3.2.3.1.2. FAILURE TO BE CATERED WITH ADEQUATE COMMUNITY CARE

Neither the consumers nor the caregivers were sufficiently provided with community care. In both areas, seven out of the eight consumers and six out of the eight caregivers in total received no community care service. They believed that they had to be catered with some services though they had no ideas about what particular types of service should be beneficial to them. A rural consumer spoke:

"I don't know how I can be helped by community care." (RP1)

3.2.3.1.3. DISCRIMINATION AGAINST PEOPLE WITH MENTAL ILLNESS AS MAJOR RETURN-TO-WORK BARRIER

One consumer and two caregivers in the rural areas, and two consumers, and one caregiver in the urban areas regarded discrimination against persons with mental illness

as the major external hurdle in returning to open employment. The rural consumer elaborated:

"In the community, everybody looks down on us. Everybody just simply looks down on me. Why? Just because we have mental illness, that's all!" (RP4)

Discrimination from employers can be clearly illustrated by the following quote:

"Employers have hesitations to hire persons with mental illness. They are afraid that they can't bear the responsibilities when any troubles occur." (UC3)

3.2.3.1.4. INADEQUATE SUPPORT TO FAMILY TO FACILITATE CONSUMERS' RECOVERY

Both groups in both areas regarded the community support to family to facilitate the consumers' recovery to be inadequate. No rural consumer received any support. There were only one rural caregiver, and one consumer and one caregiver in the urban areas said there was some brief support to them. The rural caregiver indicated that he desired to be empowered to help the consumer:

"Just like my son, he lacks psychological ventilation. We are not competent to help him in any ways and we hope the community can offer some guidance to us for this." (RC3)

3.2.3.2. DIFFERENCES BETWEEN CONSUMERS AND CAREGIVERS

Comparing with the consumers, the caregivers realized more that community care was crucial in the practical and financial aspects. The desire to be understood was expressed by the consumers only.

3.2.3.2.1. BETTER AWARENESS OF CAREGIVERS IN VALUES OF COMMUNITY CARE

Only caregivers (one rural and two urban) but no consumer realized the significance of community care and its cost effectiveness as compared with hospital care.

The rural caregiver explained why the care was important:

“There should better be some services in the community to offer advice to them (consumers). It would let them have some engagement instead of idling at home, just sitting alone with face pointing down.” (RC3)

An urban caregiver justified the value of community care from financial point of view:

“Definitely good! Treatment fees in hospitals are indeed high, those in community are lower.” (UC1)

3.2.3.2.2. DESIRE TO BE UNDERSTOOD EXPRESSED BY CONSUMERS BUT NOT CAREGIVERS

The consumers (one from urban and three from rural) desired to be better understood by the caregivers but none of the caregivers knew it at all.

A rural consumer emphasized:

"They (caregivers) must understand. Understanding is precious!" (RP4)

3.2.3.3. DIFFERENCES BETWEEN URBAN AND RURAL AREAS

Comparing with the rural areas, rehabilitation interventions and community care were provided relatively less inadequately in the urban areas. There was a disparity that both the medical insurance coverage and the financial subsidies from the government for medical expenses were somehow better in the urban areas but scarce in the rural areas. This caused family financial burden and psychological distress in the rural areas but rather not in the urban areas. Besides, poor control of mental conditions was more commonly regarded in the rural areas than in the urban areas as the main internal factor causing unemployment. As a significant type of support to the caregivers, management of caregivers' own emotions was regarded by both groups in the urban areas but by the caregiver group only in the rural areas.

3.2.3.3.1. LESS INADEQUATE REHABILITATION INTERVENTIONS IN URBAN AREAS

Only one (caregiver) out of the eight rural respondents but three (two consumers and one caregiver) out of the eight urban respondents received brief rehabilitation service.

3.2.3.3.2. LESS INSUFFICIENT COMMUNITY CARE IN URBAN AREAS

None of the eight rural respondents but three (one consumer and two caregivers) out of the eight urban respondents received community care.

3.2.3.3.3. HEALTHCARE RESOURCE DISPARITY BETWEEN URBAN AND RURAL AREAS

The allocation of healthcare resources for medication was less sufficient in the rural areas than in the urban areas. It made both the rural consumers and caregivers have financial and psychological burden. In the urban areas, two out of the four consumers and all of the four caregivers respectively reported having medical insurance coverage and government financial subsidies for the medication expenses. In contrast, no consumers and only one out of the four caregivers in the rural areas reported having the financial support. A rural caregiver explained that it was their family's financial burden due to insufficient subsidies for medication which decreased the drug compliance of the consumer and in turn caused psychological distress. She elaborated:

"He (the consumer) worries that we can no longer sustain our life when we have used up our money. He thus keeps claiming that he is not ill and so needs no medication. Actually, it is just because of the cost. This drug costs CNY 28 per pill, which is deadly expensive, in particular for us, rural people. He has no job and so no income. He is spending our money and he doesn't feel good and so stops taking the pills." (RC3)

On the other hand, urban consumers' psychological state was better maintained because of the relatively sufficient financial support from the government. A consumer highlighted:

"It (the subsidy) lessens life stress and so is beneficial to our mental conditions." (UP1)

3.2.3.3.4. POOR CONTROL OF MENTAL CONDITIONS MORE WIDELY REGARDED AS MAJOR INTERNAL BARRIER OF EMPLOYMENT IN RURAL AREAS

Poor control of mental conditions as the major internal factor deterring return-to-work was more widely regarded in the rural areas (one consumer and three caregivers) than in the urban areas (one caregiver). A rural caregiver criticized:

"His (the consumer's) mental condition is abnormal, different from others'!" (RC3)

3.2.3.3.5. MANAGEMENT OF CAREGIVERS' EMOTIONS MORE WIDELY REGARDED AS SIGNIFICANT SUPPORT IN URBAN AREAS

Support to caregivers to manage their own emotions was found to be significant by both the urban consumers and caregivers but by the rural caregivers only. An urban caregiver explained that the difficulties in managing her emotions were because of the hardship in the caring process:

"I feel very tired and stressful. I am speechless. I can't tell anybody and even if I do, none of them would really understand. Would they be able to understand when they have no such experience (caring person with mental illness)?" (UC3)

3.2.4. DISCUSSION

By exploring and comparing the views of the persons with schizophrenia and their caregivers in both the urban and rural regions in Wuxi towards the needs for psychiatric rehabilitation, this qualitative study using face-to-face interviews provided useful information that may more precisely guide the government and policy makers to tailor the psychiatric rehabilitation strategies and services. The findings could be applicable to the population of the persons with schizophrenia that over 90% of them receive care from their family (Yip, 2005).

Both the consumers and caregivers in both the urban and rural areas were noted to have unclear understanding of the concepts of rehabilitation and thus they may not be able to identify the necessary rehabilitation interventions. Despite the fact that the

duration of the illness of the persons with schizophrenia in the urban areas was much longer than that in the rural areas, both the consumer group and the caregiver group in the two areas were not aware of what particular interventions they should receive to facilitate the recovery. This probably pertains to the challenges in promoting the psychiatric rehabilitation philosophy and practices in China. Many people in the mainland still do not have adequate knowledge in psychiatric rehabilitation and recovery. To educate the consumers and their caregivers about the psychiatric services, it is essential to have concerted efforts from medical, rehabilitation, and social care professionals (Yip, 2007). Unfortunately, the workforce of the rehabilitation and social care professionals including occupational therapists and social workers is inadequate in the mainland (Li et al., 2014b). Among the small pool of the occupational therapists, most of them are working in the fields of physical disabilities (Shi & Howe, 2016), and the job market of social workers and hence their roles even almost do not exist (Sha et al., 2012). The psychoeducation provided by psychiatrists and psychiatric nurses is rather confined to the medical aspects of the mental illness, and the instillation and promotion of the rehabilitation and recovery concepts is affected. Moreover, despite the efforts to launch and promote the psychosocial rehabilitation by the experts from Hong Kong, the majority of the respondents of this study are still unaware of the corresponding developments. One of the reasons may be the shortage of resources. Only a very limited number of the psychosocial rehabilitation programs such as the Integrated Supported Employment (ISE; Tsang et al., 2009) could be supported over the past few years. They covered only a very small proportion of the pool of the potential service users, and the respondents in this study had not ever received any of the services. More funding should thus be injected to

flourish the manpower in the hospital and community settings to expand and sustain the provision of the related psychosocial interventions including ISE, psychoeducation, social skills training and case management.

This study also reveals that the consumers and the caregivers in both the urban and rural areas did not give much attention to the community care. Although the Chapter IV (Rehabilitation of mental disorders) of the China's New Mental Health Law (Standing Committee of the National People's Congress, 2013) has stipulated that community-based rehabilitation for people with mental illness should be provided, the development of the related services seems to be lagging behind. In fact, the mode of psychiatric rehabilitation has been shifted from traditional hospital-based to contemporary community-based (Thornicroft and Tansella, 2004) because of the evidential benefits of the latter. Community-based psychiatric rehabilitation is able to promote quality of life of both the persons with mental illness and their families by achieving social inclusion through the joint efforts of the stakeholders including the consumers and their caregivers, professionals, service providers and government (World Health Organization, 2004). This calls for advocating the conceptualization and hence the practice of community-based rehabilitation. There are however a number of barriers. One of the core issues is that the values of primary health care are not given due recognition in the mainland. Under the market economy, specialist services in tertiary psychiatric hospitals can attract users, especially those who are richer and those who look for better and more advanced treatment (Liu et al., 2011). Also as such, the remuneration of psychiatric specialists in these hospitals is much more attractive than that in the community settings which makes them reluctant to serve in the latter (Zhang et al., 2013). Besides, lacking good

coordination between the hospital settings and the community settings in the referral system makes the transition of the care less smooth (Royer, 2015). In this connection, the policy makers need to refine the current healthcare financing models and workforce systems in order to allocate more resources for the community care and to obtain professional guidance from overseas psychiatric rehabilitation experts for training up more community care workers and streamlining the referral procedures. As for the family caregivers, it is doubtless that they form a major support system by bearing the responsibilities of taking care of their family members with mental illness (Hou et al., 2008). They are the core member in the recovery team who collaborate with other team members in the rehabilitation interventions to facilitate the recovery process and optimize its outcomes (Colom and Vieta, 2004). They should therefore be involved whenever possible in the course of psychiatric rehabilitation including assessment of the rehabilitants' needs and then planning, implementation and evaluation of the interventions (King and Lloyd, 2007). The consumers in this study wanted their needs to be better understood by their caregivers but none of the caregivers was aware of it. It reveals that the caregivers did not recognize the importance of understanding consumers' perceived needs and it might have made the caring process more challenging as those needs could not be well satisfied (Hansson et al., 2003). This in turn may result in their poor quality of life (Chang et al., 2002).

The caregivers in both the urban and rural areas reported that limited support was provided to them to facilitate the recovery process, and one of them expressed a need for empowerment. It is similar to the situations in the Western world where the caregivers are not well empowered to enable their family members to achieve recovery goals (Ran et al.,

2005). This calls for establishment and maintenance of working alliance among the consumers, caregivers, and practitioners (Howgego et al., 2005). The professionals as the significant members in the alliance do however not duly recognize the caregivers and so the services proposed to support them are deemed neither reasonable nor necessary (Nolan & Mestheneos, 2006). The roles of caregivers cannot be made explicit when they are not sufficiently empowered to execute their functions. This in turn will further undermine their roles and eventually make their views even be more rarely acknowledged and considered by the mental health practitioners. In response to this situation, it is worthy to explore the caregivers' perspectives toward the recovery of the care recipients to enhance the practitioners' understanding of the complexities of care provision and the impacts on recovery (Family Caregiver Alliance, 2006). To achieve this in the mainland, the Perceived Rehabilitation Needs Questionnaire for Caregivers toward People with Schizophrenia (Wong et al., 2011) developed in Hong Kong may be applicable, which measures the perceived rehabilitation needs of the people with schizophrenia from their caregivers' perspectives. Findings of surveys using this tool should be able to shed light on the ways the mental health professionals can adopt to tailor make the support to caregivers to facilitate their engagement in the consumers' recovery process.

The disparity in healthcare resource utilization for psychotropic medication between the urban and rural areas is also disclosed in this study. In fact, such disparity has remained wide among provinces and within cities in the mainland except in some rich Eastern regions where the mental health service system has been reformed timely. In the under-developed regions in the Western part of the mainland, the financial resources are seriously inadequate (Liu et al., 2011). Again, the introduction of market economy under

the economic reform has encouraged the hospitals to make profits (Li et al., 2005). As hospital services target users who are richer, nearly all of the hospitals are built in the urban areas of the more affluent cities (Philips, 2000). The social insurance system is also better established in such regions and thus further catalyzes the use of the hospital services (World Health Organization, 2010). In fact, the consumers in both the urban and rural areas of Wuxi urgently need affordable healthcare services. With only ¥51,711 GDP per capita (Global Times, 2012), the median total healthcare cost for schizophrenia in Jiangsu province (where Wuxi is under) in 2010 was as much as ¥10,765 per hospital admission in which medications constituted much (Montgomery et al., 2013). It is even more alarming for the situations in the rural areas where the consumers' accessibility to the quality healthcare services is deterred by not only the remote geographical location but also the scarce income. It is thus of no surprise to note in this study that both the consumers and caregivers in the rural areas had experienced financial burdens and the resulting psychosocial hardship. Achieving medical insurance coverage for all potential service users seems to be a solution. Unfortunately, even with considerable efforts to increase coverage, it does not catch up with the increasing number of people with mental illness in China (Deloitte, 2015). Strengthening the current primary mental healthcare system may be an alternative. Community mental health services in general cost less than hospitalization and allow easier geographical access (Edwards, 2014). Locally driven research should be conducted to inform the policy makers of the directions to develop financially viable and sustainable community-based services in the rural regions through, for example, procurement of cost-effective anti-psychotics, and training of allied health professionals including occupational therapists and social workers.

Finally, the consumers and caregivers in both the urban and rural areas experienced discrimination against schizophrenia in the job seeking and maintenance process. It is not unexpected as stigma occurs once a person's mental illness is made known, and rejections against him will then start and perpetuate even when his symptoms have subsided (Byrne, 2000). This induces big difficulties in returning to work and in turn reintegrating into the community. This could partly explain the prolonged high unemployment rates of persons with schizophrenia in both the urban and rural regions in China which are significantly higher than those without the illness (Montgomery et al., 2013). Apart from this external factor, a major internal factor widely regarded in the rural areas is the poor control of the psychiatric positive and negative symptoms. This is not an unreasonable association as mental states can reduce one's functional capacity to perform at work (Center for Psychiatric Rehabilitation, 2016). Owing to the insufficiency of the supply of appropriate psychotropic medications in the rural areas, caregivers might have clearly observed and understood the impacts of unstable mental status of the consumers on their daily functioning including productivity. Nonetheless, one should also realize the multifaceted nature of the obstacles of employment that involve both internal and external factors (Razzano et al., 2005; Stefan, 2002). The consumers and their caregivers should be guided to become more aware of the mixed causes and hence the multi-factorial management to enhance their compliance and engagement in the vocational rehabilitation interventions.

3.2.5. IMPLICATIONS OF FINDINGS

The findings of this phase of study may help enrich the field of knowledge in the perception of the persons with schizophrenia and their caregivers in the urban and rural areas of Wuxi towards the needs for psychiatric rehabilitation services. This may provide some ideas to help fine-tune the mental health policies and the corresponding strategies in Wuxi to benefit this clientele and their caregivers. With careful consideration of the possible socio-cultural differences, the findings may also serve as valid references for the mental health researchers and clinicians in other Chinese societies.

3.2.6. LIMITATIONS

The relatively small sample size and the convenience sampling might have limited the depth of the findings of this study. While there seems no consensus on how many subjects should be enough, Francis et al (2010) propose a '10+3' formula to ensure data saturation which is to conduct additional three interviews after every 10 interviews to evaluate if any new insights are to be generated. As for the presence of the researcher(s) in the data collection, it is usually inevitable but it may affect the respondents' responses due to social desirability effect and in turn undermine the validity of the findings (Anderson, 2010). Such bias should have been minimized as I was the only one conducting all of the interviews and that I did not belong to the center, and the interviewees and I did not know each other. Thus, the interviewees might not intend to give socially pleasant answers in order not to harm their relationship with the healthcare professionals in the center.

3.3. PHASE THREE: SURVEY

3.3.1. INTRODUCTION

Given the complexity of the psychiatric rehabilitation per se and its associated societal issues specific to mainland China, findings from mental health policy research are crucial for developing evidence-based psychiatric rehabilitation policies and practices relevant to its unique socio-cultural contexts not only among provinces but also more specifically between the urban and rural regions within a province. As mentioned in Chapter One, there has been a health inequality between the more developed urban regions and the less developed rural regions in China due to the continuous socio-economic revolution (Griffiths, 2008) which results in an imbalance of allocation of financial resources. The better infrastructure in terms of the availability of psychiatric hospitals together with the advanced health insurance systems in the urban areas make the mental health services more accessible there (Philips, 2000; World Health Organization, 2010). The situations are in reverse in the rural areas. Timely assessment of the needs of the corresponding mental healthcare service users in different geographical parts should therefore be conducted before any sustainable mental health systems and services for the whole population with schizophrenia in mainland China can be established and consolidated (Liu et al., 2011). Scientific measurement of the rehabilitation needs of people with schizophrenia and their caregivers through standardized assessment tools is the key to systematically understanding their concerns. In order to tailor psychiatric rehabilitation interventions in the mainland, the rehabilitation needs of the corresponding service users have to be explored respectively (Zhang et al., 2014a). A scientific "needs-led" measurement approach (Cleary et al., 2006) can facilitate this process. This approach

is a major practice in making decisions on health policies (Evans et al., 2000). As reported in the first section of this chapter, the two questionnaires developed in Hong Kong, PRNQ-S and PRNQ-C, measuring the rehabilitation needs of persons with schizophrenia and their caregivers respectively have been culturally validated in Wuxi. The corresponding Wuxi versions named PRNQ-S-WX and PRNQ-C-WX have become the first of the kinds of standardized assessment tools in the mainland (Li et al., 2014a; Li et al., 2014c). These scales contribute to the scientific and systematic measurement of the needs and thus lay a good foundation for survey studies. The qualitative study as reported in the previous section in this chapter has revealed some insightful views of the individuals with schizophrenia and their caregivers towards the needs for psychiatric rehabilitation in the urban and rural areas of Wuxi. The findings should be useful for supplementing and validating information (as a means of triangulation) in questionnaire studies (Laforest & Bouchard, 2009). This study has taken a further step to examine and compare the rehabilitation needs of these two groups of service users in the urban and rural regions of Wuxi through a quantitative survey using PRNQ-S-WX and PRNQ-C-WX respectively. The identification of the perceived importance of the needs would enable the review of the adequacy and preciseness of the rehabilitation services in addressing the users' concerns and hence help prioritize the provision. By comparison, the urban-rural differences of the needs can be revealed. It can also help fine-tune the directions of the existing psychiatric rehabilitation policies to better allocate the healthcare resources for the services to deal with the issues specific to the socio-cultural features of the two regions respectively. One example pertains to the concerns about return-to-work of the persons with schizophrenia. The consumers regarded employment

as a means to establishing relationship with others but the caregivers rather concerned about the monetary return to relieve the family financial burden (Yu et al., 2016). Besides, the poor control of mental status was more widely regarded in the rural areas than in the urban areas as the major internal factor hindering employment, and the keen competition in open job market was regarded more commonly as the main external factor causing unemployment in the urban areas than in the rural areas (Tsui & Tsang, under review). Failure to address such kinds of discrepancies in clinical practice may prolong the stress of both the consumers and the caregivers and thus pose challenges in the course of vocational rehabilitation.

Equity is one of the six major principles for organizing mental health services (World Health Organization, 2003) which emphasizes that the access to required services is needs-driven and the geographic disparities have to be addressed by satisfying the needs of the people in the urban and rural areas respectively. The right to receive interventions has to base on the needs for services but not the affordability or the geographic residency, and thus the healthcare resources have to be distributed fairly across the population to optimize the users' health gains (Richard et al., 2009). Being still a developing country, financial support is indeed necessary for the people with schizophrenia in China in particular those living in the rural regions to get access to the appropriate mental health services (Ran et al., 2017). This is consistent with the notion of the client-centered approach that the services should be highly congruent with and responsive to the needs of the clients according to their unique social and economic conditions (Laine & Davidoff, 1996). In fact, the socio-economic background varying with regions correlates with the levels of mental health needs of the corresponding

residents (Saxena et al., 2007). Nevertheless, it is not uncommon that persons who are most in need of mental health services are least probable or able to ask for the services and therefore they are usually neglected by the policy makers when the resource allocation for services is being prioritized (Pilbeam et al., 2014). This issue is probably related to their mental health literacy. Mental health literacy is defined as a person's knowledge and beliefs about mental illness, which help him realize, manage or prevent the disorder (Jorm et al., 1997). In China, this literacy is lower in the rural residents than the urban ones, which is associated with the lower education, older age and poverty in the rural areas (Yu et al., 2015). This highlights the importance of the health policy makers in recognizing the impacts of mental health literacy on the mental health service usage which otherwise may lead to some mismatch between the service provision and the actual needs of the users including the individuals with schizophrenia and their caregivers in the respective geographic locations. This phenomenon refers to the Inverse Care Law (Hart, 1971) that people who have the greatest need of the service are least likely to be provided with it and vice versa. In other words, there is a deviation of resource utilization for benefiting the real service users. It may result in tightening the already scarce resources which may then trim the existing service pool as a whole, and eventually limit the access of all users (both urban and rural) to the essential interventions.

In this regard, it is of utmost importance to investigate the variations in the perception of the rehabilitation needs between the urban and rural service users.

This study therefore aimed to identify the perceived importance of the rehabilitation needs of the persons with schizophrenia and the caregivers respectively, and the differences of these needs between the urban and rural counterparts.

The four hypotheses grouped into two sets in this phase of study are related to the urban-rural difference. The first two hypotheses are:

1) “There is a significant difference between the urban consumers and the rural consumers in the level of perceived importance of the rehabilitation needs (as indicated by the means of each of the 17 factors in PRNQ-S-WX)”, and

2) “There is a significant difference between the urban caregivers and the rural caregivers in the level of perceived importance of the rehabilitation needs (as indicated by the means of each of the eight factors in PRNQ-C-WX)”.

The other two hypotheses include:

1) “In PRNQ-S-WX, there is/are demographic variable(s) other than regions including gender, age, educational level, marital status, living status, employment status, and length of receiving mental health service predicting the score in the factor(s) having urban-rural difference”, and

2) “In PRNQ-C-WX, there is/are demographic variable(s) other than regions including gender, age, educational level, marital status, living status (living with the consumer or not), employment status, and length of contacting mental health service predicting the score in the factor(s) having urban-rural difference”.

The findings should be able to assist the policy makers to sharpen the mental health strategies and interventions to satisfy the rehabilitation needs of the people with schizophrenia and their caregivers, and hence promote their quality of life.

3.3.2. METHOD

3.3.2.1. PARTICIPANTS

3.3.2.1.1. INDIVIDUALS WITH SCHIZOPHRENIA

By convenience sampling, a total of 375 participants were recruited from Wuxi Mental Health Centre to complete the PRNQ-S-WX. They were the individuals having diagnosed with schizophrenia for at least one year by their case psychiatrists according to criteria of DSM-IV. They were symptomatically stable, aged 18 or above, and fluent in Putonghua. Anyone found to be unable to clearly understand the questions or respond to the questions was excluded. The demographic information of the respondents is summarized in Table 8.

Table 8
Demographic information of the participants in PRNQ-S-WX

	n=375 (%)
Area	
Urban	184 (49.1%)
Rural	191 (50.9%)
Gender	
Male	195 (52.0%)
Female	180 (48.0%)
Age	
18-25	42 (11.2%)
26-35	91 (24.3%)
36-45	110 (29.3%)
46-55	78 (20.8%)
56 or above	54 (14.4%)
Educational level	
Illiterate	15 (4.0%)
Primary	76 (20.3%)
Secondary	202 (53.9%)
Tertiary or above	60 (16.0%)
Others	22 (5.8%)
Marital status	
Single	151 (40.3%)
Married	163 (43.4%)
Divorced	52 (13.9%)
Widowed	9 (2.4%)
Living condition	
Live alone	55 (14.7%)
With family members	312 (83.2%)
Friends	3 (0.8%)
Others	5 (1.3%)
Employment status	
Open employment	151 (40.2%)
Supported employment	33 (8.8%)
Sheltered Workshop	4 (1.1%)
Unemployed	141 (37.6%)
Others	46 (12.3%)
Length of contacting mental health service	
2 years or below	57 (15.2%)
2 – 5 years	92 (24.5%)
5 – 10 years	94 (25.1%)
10 years or above	132 (35.2%)

3.3.2.1.2. CAREGIVERS

A total of 250 participants recruited from Wuxi Mental Health Centre by convenience sampling were invited to complete the PRNQ-C-WX. They were the caregivers of persons with schizophrenia having taken up the caring role for at least one year. They were aged between 18 and 60, and fluent in Putonghua. Anyone found to be unable to clearly understand the questions or respond to the questions was excluded. Table 9 summarizes the demographic information of the respondents.

Table 9
Demographic information of the participants in PRNQ-C-WX

	n = 250 (%)
Area	
Urban	125 (50.0%)
Rural	125 (50.0%)
Gender	
Male	121 (48.4%)
Female	124 (49.6%)
Age	
18-25	14 (5.6%)
26-35	41 (16.4%)
36-45	81 (32.4%)
46-55	65 (26.0%)
56 or above	49 (19.6%)
Educational level	
Illiterate	6 (2.4%)
Primary	57 (22.8%)
Secondary	122 (48.8%)
Tertiary or above	53 (21.2%)
Others	12 (4.8%)
Marital status	
Single	28 (11.2%)
Married	185 (74.0%)
Divorced	19 (7.6%)
Widowed	18 (7.2%)
Living with patient	
Yes	216 (86.4%)
No	34 (13.6%)
Employment status	
Employed	188 (75.2%)
Unemployed	62 (24.8%)
Length of contacting mental health service	
2 years or below	21 (8.4%)
2 – 5 years	75 (30.0%)
5 – 10 years	68 (27.2%)
10 years or above	86 (34.4%)

3.3.2.2. INSTRUMENTS

3.3.2.2.1. PRNQ-S-WX

This questionnaire consisted of three sections. The first section contained 75 items grouped into 17 factors to assess the perceived importance of the rehabilitation needs of a respondent with schizophrenia. The 17 factors were “Occupation”, “Behavior and impulse control”, “Family and Discrimination”, “Social welfare and Housing”, “Self-care”, “Leisure”, “Stress management”, “Medical services and treatment”, “Social security”, “Social and intimate relationship”, “Mental health knowledge”, “Treatment adherence”, “Symptom management”, “Psychosocial care”, “Community rehabilitation”, “Emotion management” and “Education”. The respondent was asked to rate his perceived importance of the need in each item using a five-point Likert scale, with 1 denoting ‘never important’, 2 denoting ‘seldom important’, 3 denoting ‘sometimes important’, 4 denoting ‘usually important’, and 5 denoting ‘always important’. He/she was also required to rate to what extent his/her need was satisfied in each item if he had ever received the corresponding service(s), following a five-point Likert scale, with 1 denoting ‘never satisfied’, 2 denoting ‘seldom satisfied’, 3 denoting ‘sometimes satisfied’, 4 denoting ‘usually satisfied’ and 5 denoting ‘always satisfied’. The second section required the respondent to rate his perceived importance of various psychiatric rehabilitation services using a five-point Likert scale, with 1 denoting ‘never important’, 2 denoting ‘seldom important’, 3 denoting ‘sometimes important’, 4 denoting ‘usually important’ and 5 denoting ‘always important’. There were a total of 30 items which were divided into eleven categories including Vocational rehabilitation, Community rehabilitation, Family intervention, Residential placement, Psychotherapy, Psychotropic

medication, Self management program, Social activity, Social welfare, Emergency service, and Others. Similarly, the respondent also had to rate to what extent his/her need was satisfied in each item if he/she has ever received the corresponding service(s), using a five-point Likert scale, with 1 denoting ‘never satisfied’, 2 denoting ‘seldom satisfied’, 3 denoting ‘sometimes satisfied’, 4 denoting ‘usually satisfied’, and 5 denoting ‘always satisfied’. An open-ended question is included for recording the respondent’s opinions towards the rehabilitation needs or service provision. In the final section, the respondent was asked to provide his own demographic information.

3.3.2.2.2. PRNQ-C-WX

There were three sections in this questionnaire. The first section consisted of 50 items grouped into eight factors, namely, “Leisure and Social life”, “Stress management”, “Caring skills”, “Social support”, “Security”, “Burden reduction and Financial support”, “Work and Responsibility” and “Accommodation” for assessing a caregiver’s perceived importance of the rehabilitation needs. The respondent was asked to rate his perceived importance of needs in each item following a five-point Likert scale, with 1 denoting ‘never important’, 2 denoting ‘seldom important’, 3 denoting ‘sometimes important’, 4 denoting ‘usually important’, and 5 denoting ‘always important’. The respondent was also asked to rate to what extent his/her need was satisfied in each item if he had ever received the corresponding service(s), using a five-point Likert scale, with 1 denoting ‘never satisfied’, 2 denoting ‘seldom satisfied’, 3 denoting ‘sometimes satisfied’, 4 denoting ‘usually satisfied’ and 5 denoting ‘always satisfied’. In the second section, the

respondent was requested to rate his perceived importance of various psychiatric rehabilitation services in a total of 13 items divided into seven categories, namely, Family rehabilitation, Psychotherapy, Self management, Social activity, Social welfare, Emergency services, and Others, using a five-point Likert scale, with 1 denoting 'never important', 2 denoting 'seldom important', 3 denoting 'sometimes important', 4 denoting 'usually important' and 5 denoting 'always important'. Similarly, the respondent is also required to rate to what extent his/her need was satisfied in each item if he had ever received the corresponding service(s), using a five-point Likert scale, with 1 denoting 'never satisfied', 2 denoting 'seldom satisfied', 3 denoting 'sometimes satisfied', 4 denoting 'usually satisfied', and 5 denoting 'always satisfied'. The respondent was required to write down his/her opinions towards the rehabilitation needs or service provision in response to an open-ended question. The respondent had to provide his/her own demographic information in the final section.

3.3.2.3. DATA COLLECTION

To ensure the validity of the results, independent assessors including qualified psychiatrists, mental health nurses, and occupational therapists with at least three years of frontline experience were trained to use the PRNQ-S-WX and PRNQ-C-WX respectively. The research group of the Neuropsychiatric Rehabilitation Laboratory led by a professor in occupational therapy provided a certificated training workshop for them and they had to satisfy the requirement in order to be qualified to administer the questionnaires. Prior consent was obtained from each participant before an assessor was

randomly selected to administer the instrument and record the results accordingly through a face-to-face interview. To ensure privacy, each interview was conducted in a closed room of the centre and it lasted for about 45 to 60 minutes for PRNQ-S-WX and 30 to 45 minutes for PRNQ-C-WX.

3.3.2.4. DATA ANALYSIS

Descriptive and frequency statistics were used to summarize the demographic data of the participants and the results of the surveys of PRNQ-S-WX and PRNQ-C-WX. Profile on the importance of the perceived rehabilitation needs of the consumers and caregivers was indicated by the mean scores of each of the factors (in a 5-point Likert scale) in both questionnaires. In each questionnaire, binary logistic regression was used to investigate the factors that predicted the participants in the urban or rural regions. In each of these factors, ordinal regression was adopted to find out which of the demographic variable(s) determined the score. Independent *t* test or one-way ANOVA was then deployed to test the difference of its means within the demographic variable with two or multiple choices respectively. For example, if the factor “Security” was found to predict the caregivers in the urban or rural regions in the binary logistic regression, the ordinal regression was then used to investigate which of the demographics of the caregivers determined the scores in this factor. If age was the demographic variable that determined the scores in this factor, one-way ANOVA was used to investigate if there was any significant difference of the means among the five age groups of the caregivers. The Nagelkerke R Square was more commonly reported than Cox and Snell’s R-Square as the range was from 0 to 1 in the former but not in the latter and thus it was a more reliable

measure of the relationship between the predictors and the prediction (Burns & Burns, 2008). The Exp(B) value was the odds ratio which could be interpreted as a percentage change in odds for the dependent variable for a unit change in the associated independent (predictor) variable (Field, 2009). Level of significance was set as 0.05. All data was analyzed using the Statistical Package for the Social Sciences (SPSS) version 23.

3.3.3. RESULTS

3.3.3.1. PERCEIVED REHABILITATION NEEDS OF CONSUMERS

The five-point Likert scale indicated the levels of importance with 1 denoting least important and 5 denoting most important. In PRNQ-S-WX, the total mean of the 17 factors was 3.73 and the means of the individual factors ranged from 3.02 (Leisure) to 4.35 (Emotional management). Eight out of the 17 factors were rated over 4, and none scored below 3. In descending order, the eight factors were “Emotional management”, “Social security”, “Psychosocial care”, “Treatment compliance”, “Mental health knowledge”, “Community Rehabilitation”, “Symptom management” and “Stress management”. As for the urban consumers, the total mean was 3.96 and the means of the factors ranged from 3.31 (Leisure) to 4.50 (Emotional management). None of the factors was rated below 3. Eight factors scored over 4 which in descending order were “Emotional management”, “Psychosocial care”, “Treatment adherence”, “Social security”, “Community Rehabilitation”, “Mental health knowledge”, “Stress management” and “Symptom management”. In the rural ones, the total mean was 3.52 and the means ranged from 2.71 (Behavior and impulse control) to 4.24 (Social security). In descending order, the two factors scored over 4 were “Social security” and “Emotional management”.

In ascending order, the four factors rated below 3 were “Behavior and impulse control”, “Leisure”, “Education” and “Social and intimate relationship”. The factors scored the highest and the lowest were not the same between the urban and rural respondents. Comparing the urban and the rural areas, the urban respondents scored higher overall and in all factors than the rural ones did. Significant differences were found in all factors except “Social security”. “Social security” and “Emotional management” were the two factors that both urban and rural respondents rated over 4. The four factors with means lower than 3 including “Behavior and impulse control”, “Leisure”, “Education” and “Social and intimate relationship” were all found in the rural respondents only. The statistics are summarized in Table 10.

Table 10
Mean scores of the subscales of PRNQ-S-WX

Name of subscales (Part I of PRNQ-S-WX)	Number of items	*n* = 375			
		Whole	Urban	Rural	*p*
1. Occupation	13	3.75	3.97	3.55	0.001*
2. Behavior and impulse control	6	3.07	3.43	2.71	<0.001*
3. Family and Discrimination	10	3.78	3.99	3.59	<0.001*
4. Social welfare and Housing	8	3.29	3.56	3.02	<0.001*
5. Self-care	4	3.51	3.78	3.25	<0.001*
6. Leisure	3	3.02	3.31	2.75	<0.001*
7. Stress management	4	4.03	4.25	3.81	<0.001*
8. Medical services and treatment	4	3.56	3.83	3.39	<0.001*
9. Social security	3	4.29	4.34	4.24	0.226
10. Social and intimate relationship	5	3.16	3.42	2.90	<0.001*
11. Mental health knowledge	4	4.10	4.27	3.93	<0.001*
12. Treatment adherence	3	4.16	4.37	3.95	<0.001*
13. Symptom management	3	4.04	4.24	3.84	<0.001*
14. Psychosocial care	1	4.19	4.41	3.98	<0.001*
15. Community rehabilitation	1	4.09	4.28	3.92	0.002*
16. Emotion management	1	4.35	4.50	4.20	0.004*
17. Education	2	3.09	3.45	2.76	<0.001*
Total	75	3.73	3.96	3.52	<0.001*

*significant at p=0.05 level
Response choices for PRNQ-S-WX: 1 = “never important”; 2 = “seldom important”;3= “sometimes important”; 4 = “usually important”; 5 = “always important”

By binary logistic regression, the two factors, namely, “Psychosocial care” and “Behavior and impulse control”, respectively predicted the consumers in the urban or rural regions. The statistics are summarized in Table 11.

Table 11
Statistics of binary logistic regression of PRNQ-S-WX

Factor with urban-rural prediction	Nagelkerke R Square	Exp(B)
Psychosocial care	0.046	0.707 (p=0.01)
Behavior and impulse control	0.097	0.653 (p<0.001)

In “Psychosocial care”, the Nagelkerke R Square was 0.046 that indicated the relationship of 4.6% between this factor and the urban-rural prediction. It was 0.097 in “Behavior and impulse control” and it showed the relationship of 9.7% between this factor and the urban-rural prediction. Combining “Psychosocial care” and “Behavior and impulse control”, the Nagelkerke R Square of was 0.135 that indicated the relationship of 13.5% between these two factors and the urban-rural prediction.

In this study, the Exp(B) value was regarded as the percentage change in odds for the urban or rural membership for a unit change in the Likert scale of the factor predicting the urban-rural categorization. With the urban membership coded as 0 and the rural membership coded as 1, the Exp(B) value was 0.707 (p=0.01) in “Psychosocial care” which indicated a decrease in odds of 29.3% of belonging to the rural group for every one unit increase in the scale of the factor. As for “Behavior and impulse control”, the Exp(B) value was 0.653 (p<0.001) which implied the odds of belonging to the rural group decreased by 34.7% for each unit increase in the scale of the factor. Hence, these findings

demonstrated that urban consumers tended to have higher levels of the perceived importance in both factors than the rural ones did.

In both factors, higher levels of the perceived importance were found in the urban consumers. In “Psychosocial care”, the mean scores were 4.41 and 3.98 in the urban and rural ones respectively and the difference was significant ($p<0.001$). As for “Behavior and impulse control”, the urban ones scored 3.43 and the rural ones scored 2.71. The difference was significant ($p<0.001$).

By ordinal regression, the demographics that determined the scores in the factors having predicted urban-rural categorization could be found. Employment status was the demographic variable determining the levels of the perceived importance in the factors “Psychosocial care” and “Behavior and impulse control” respectively. The Nagelkerke R Square was 0.094 in “Psychosocial care” which showed the relationship of 9.4% between the employment status and this factor. It was 0.137 in “Behavior and impulse control” and it indicated the relationship of 13.7% between the employment status and this factor.

The scores of the factor differed significantly in the consumers with different employment status. In “Psychosocial care”, the unemployed ones had the highest level (4.48) whereas those in supported employment had the lowest (3.39). The difference was significant ($p<0.001$). In “Behavior and impulse control”, those in sheltered workshop had the highest level (3.50) and the unemployed had the lowest (2.95). The difference was significant ($p<0.001$).

3.3.3.2. PERCEIVED REHABILITATION NEEDS OF CAREGIVERS

With the same Likert scale denoting the levels of importance, the means of the eight individual factors in PRNQ-C-WX ranged from 2.75 (Accommodation) to 4.39 (Stress management) and the total mean was 3.77. Three out of the eight factors were scored over 4 which in descending order were “Stress management”, “Caring skills” and “Social support”. “Accommodation” was the only factor rated below 3. In the urban caregivers, the total mean was 3.94 and the means of the individual factors ranged from 3.04 (Accommodation) to 4.50 (Stress management). There were five factors rated over 4. They in descending order were “Stress management”, “Caring skills”, “Social support”, “Security” and “Burden reduction and Financial support”. No factor was scored below 3. As for the rural ones, the means ranged from 2.46 (Accommodation) to 4.28 (Stress management), and the total mean was 3.61. In descending order, the two factors rated over 4 were “Stress management” and “Caring skills”. In ascending order, “Accommodation” and “Leisure and Social life” were the factors scored below 3. Both the urban and rural respondents scored “Stress management” the highest and “Accommodation” the lowest. The urban respondents rated significantly higher overall and in all factors than the rural ones did. “Stress management” and “Caring skills” were the two factors that both urban and rural respondents rated over 4. The two factors with means lower than 3 were “Accommodation” and “Leisure and Social life”, and both were found in the rural respondents only. The descriptive statistics are summarized in Table 12.

Table 12
Mean scores of the subscales of PRNQ-C-WX

Name of subscales (Part I of PRNQ-C-WX)	Number of items	*n* = 250			
		Whole	Urban	Rural	*p*
1. Leisure & Social life	7	3.17	3.38	2.97	0.003*
2. Stress management	8	4.39	4.50	4.28	0.006*
3. Caring skills	7	4.13	4.24	4.03	0.011*
4. Social support	6	4.05	4.17	3.94	0.032*
5. Security	8	3.94	4.16	3.73	<0.001*
6. Burden reduction & Financial support	7	3.96	4.11	3.82	0.008*
7. Work & Responsibility	5	3.76	3.91	3.62	0.012*
8. Accommodation	2	2.75	3.04	2.46	<0.001*
Total	50	3.77	3.94	3.61	<0.001*

*significant at *p*=0.05 level
Response choices for PRNQ-C-WX: 1 = "never important"; 2 = "seldom important";3= "sometimes important"; 4 = "usually important"; 5 = "always important"

By binary logistic regression, "Security" and "Accommodation" were found to be the two factors respectively which predicted the caregivers in the urban or rural regions. The statistics are summarized in Table 13.

Table 13
Statistics of binary logistic regression of PRNQ-C-WX

Factor with urban-rural prediction	Nagelkerke R Square	Exp(B)
Security	0.090	0.571 (*p*=0.002)
Accommodation	0.081	0.706 (*p*=0.004)

In "Security", the Nagelkerke R Square was 0.090 that indicated the relationship of 9.0% between this factor and the urban-rural prediction. It was 0.081 in "Accommodation" and it showed the relationship of 8.1% between this factor and the

urban-rural prediction. The Nagelkerke R Square of was 0.131 when combining “Security” and “Accommodation”. It showed the relationship of 13.1% between these two factors and the urban-rural prediction.

The urban membership was coded as 0 and the rural membership was coded as 1. The Exp(B) value was 0.571 ($p=0.002$) in “Security” and it indicated a decrease in odds of 42.9% of belonging to the rural group for each unit increase in the scale of the factor. In “Accommodation”, the Exp(B) value was 0.706 ($p=0.004$) implying that the odds of belonging to the rural group decreased by 29.4% for every one unit increase in the scale of the factor. In other words, these findings showed the tendency of having higher levels of the perceived importance in both factors in the urban caregivers than in the rural ones.

The urban ones had a higher level than the rural ones did in both factors. In “Security”, the scores were 4.16 and 3.73 in the urban and rural ones respectively and the difference was significant ($p<0.001$). As for “Accommodation”, the urban ones scored 3.04 and the rural ones scored 2.46. The difference was significant ($p<0.001$).

The demographics that determined the scores in the factors having predicted urban-rural categorization could be found by using ordinal regression. Age was the demographics determining the score in the factor “Security”. The Nagelkerke R Square was 0.028 that indicated the relationship of 2.8% between the age and this factor. In ascending order, the caregivers of the youngest age group had the lowest level (3.46) and the oldest had the highest (4.04). Significant difference was found between the youngest group and the oldest group ($p=0.016$).

No demographic variable was noted to determine the score in the factor “Accommodation”.

3.3.4. DISCUSSION

This phase of study yielded intriguing findings on the perceived rehabilitation needs of the persons with schizophrenia and the caregivers in Wuxi, which added to the existing knowledge in this area.

In general, there were more factors rated over 4 in the urban respondents than in the rural counterparts. Among the 17 factors in PRNQ-S-WX, there were eight such factors in the urban consumers but only two in the rural ones. As for PRNQ-C-WX, only two out of the eight factors were noted in the rural caregivers but five in the urban ones. This difference is probably associated with the poor mental health literacy in the rural regions of China due to the lower education, older age, and poverty (Yu et al., 2015). It is not uncommon to note that neither the consumers nor caregivers in the rural areas have even a basic understanding of the illness including its nature and the ways to handle it. They may hence get no clues of what they should request to facilitate recovery. While further verification is needed, it is worth allocating resources for strengthening the public education on mental health and mental illness in the rural regions with consideration of the residents' average educational level such that the delivery strategies can help them grasp the knowledge more easily. Besides, in order to prevent mismatch between the service provision and the actual needs of the users in the rural places, the health policy makers and the service providers should be alert of the possible impacts of the users' poor mental health literacy on their identification and selection of the mental health services crucial for promoting recovery.

3.3.4.1. PERCEIVED IMPORTANCE OF THE NEEDS IN PEOPLE WITH SCHIZOPHRENIA

3.3.4.1.1. PROFILE OF THE FACTORS

Among the 17 factors, “Emotional management” was ranked the highest. It is not surprising as individuals with schizophrenia generally have severe impairment in both emotion perception and contextual processing (Monkul et al., 2007). They usually have difficulties in understanding and describing their emotions, and they cannot precisely analyze the contexts of various social situations and hence fail to respond emotionally in a socially appropriate manner (Kimhy et al., 2012). In fact, these kinds of deficits hinder their recovery by deterring social inclusion. As a significant determinant of social inclusion, social functioning of persons with schizophrenia has been found to be closely correlated with their competencies to clearly identify and suitably express their emotions (Kamel & Ali, 2016). Failure to regulate emotions may result from the inability to process and control a secondary emotional reaction originated from the primary internal thoughts (Greenberg & Leone, 2006). In this connection, temper outburst of a consumer, for example, may be due to his incompetency to mediate an emotional reaction such as feeling of frustration and hopelessness that is secondary to self-stigma. Healthcare professionals should thus consider this mechanism when devising strategies to help the consumers manage their emotions. Cognitive-behavioral therapy can be applied to let them verify and mediate the factors (e.g., discrimination) associated with emotional disturbances to lessen the resulting behaviors such as agitation. Mindfulness practice including breathing exercise and muscle relaxation techniques should be able to regulate their negative emotions through some psychological and physiological mechanisms.

There were two out of the 17 factors that both urban and rural consumers rated over 4. One was “Emotional management” which has been discussed above. The other was “Social security” which pertains to the availability of financial assistance provided in the community. In fact, the security of persons with schizophrenia has been severely crippled by the poverty in China which is further worsened by the insufficient provision of medical resources that they cannot receive effective treatment due to financial difficulties (Larson et al., 2014). The core problem is the lack of mature healthcare financing models. Having to shoulder the huge medical expenditure has made many patients and their families fall into poverty (Watts, 2007). Being unable to afford was found to be the major reason preventing the people with schizophrenia in the mainland in particular the rural ones from seeking medical care or even making them refuse to be hospitalized when advised (Kandrakonda et al., 2014). It in turn largely impedes the prognosis of the consumers (Ran et al., 2003). This parallels with some of the qualitative findings from the consumers and caregivers in Phase Two as described and discussed earlier in this chapter. Universal health coverage may be a solution as it can enable all people irrespective of their socioeconomic status to access to the needed health services (Evans & Etienne, 2010). Expansion of universal health coverage has been noted to enhance the self-perceived psychological health of the consumers (Liang & Lu, 2014). Along this line, the rural consumers’ psychological impact such as anxiety, distress, and desperation resulting from the urban–rural disparity in the availability of and affordability to the psychiatric services can be alleviated by widening the universal health coverage. To strengthen the healthcare security for the individuals with schizophrenia in particular those living in the rural regions, the policy makers and relevant stakeholders including

insurance companies have to explore the means to synergize the multiple insurance systems such as the Basic Healthcare Insurance, the Critical Illness Insurance Program for Urban and Rural Residents, Medical Aid, and Medical Emergency Aid (Xiong & Phillips, 2016). In addition, primary mental health care services may also help as they are more financially viable than psychiatric hospital services and thus benefit the three stakeholders including the government, consumers and caregivers in various ways. Treating mental illnesses in the primary care settings can be less costly. In general, the costing for operating community units such as those run by non-government organizations is lower than hospitals which means that more services can be provided even with the same budget from the government, and the consumers and caregivers can therefore pay less (World Health Organization, 2008). Those living in the rural areas can also save the travelling expenses that they do not need to go to distant urban places for the required services. The government should thus explore the feasibility of adopting the purchase mode to encourage non-government organizations to develop community-based psychiatric rehabilitation services (Xiong & Phillips, 2016). It is worth further exploring the feasibility of implementing this contemporary primary care practice.

3.3.4.1.2. DIFFERENCES WITH DEMOGRAHICS

Other than the general concerns, significant differences across the demographic variables were found in some factors.

With the regression analyses, the results have supported the hypotheses that the factors “Psychosocial care” and “Behavior and impulse control” respectively predicted the consumers in the urban or rural regions, and the employment status determined the

scores in these two factors respectively.

3.3.4.1.2.1. PSYCHOSOCIAL CARE

The consumers in different regions and with different employment status respectively varied significantly in the levels of perceived importance in the factor "Psychosocial care". The urban ones perceived a higher level of importance than the rural ones did. Those who were unemployed had the highest level and those in supported employment had the lowest.

"Psychosocial" refers to the strong connection between the psychological aspects of one's experience and his wider social experience, and this combination contributes to the psychological wellness through attaining a sense of security from being in a safe and supportive environment (British Medical Association, 2011). Discrimination against people with mental illness is more serious in the urban areas than the rural areas (Girma et al., 2014). It means a more unsafe and unsupportive atmosphere in the former and the resulting stress and burdens induced to the consumers can shred the psychological security of the consumers there more largely (Larson & Corrigan, 2008; Meyer, 2003). While anti-discrimination campaigns to tackle public stigma need continuous modifications with reference to the evidence from the related cost-effective studies, consumer-defined recovery focusing how the persons with mental illness redefine their identity and redesign their life (Picco et al., 2016) can help prevent self-stigma and in turn maintain their psychosocial wellness.

Besides, the consumers across the employment status had different levels of the perceived importance of psychosocial care in this study with those unemployed having

the highest and those in supported employment the lowest. In fact, stable employment is crucial for not only attaining financial independency but also achieving recovery through re-constructing normal life (Malhotra & Sachdeva, 2005). Supported employment is a critical step leaving the stage with poor vocational competency and productivity, and gearing towards the open employment with potentially better prospects. It makes the consumers currently in supported employment strive to do well in their duties, and it reflects their desire to be psychologically safe. In fact, it echoes well with the second layer of the Maslow's Hierarchy of Needs (Maslow, 1943). It pertains to the "Safety needs" in which job security is one of the major components. Psychosocial care is however closely related to the layer subsequent to "Safety needs" which is "Love and belonging". As the needs in each stage should be satisfied before proceeding to the next, it is not surprising to note that the consumers having supported employment concern much about the job security rather than the psychosocial care. It is worth conducting further research for verification. Nevertheless, the caregivers should try to be aware of the psychosocial needs of those consumers in the supported employment during the job consolidation process and offer support whenever necessary. They should understand the unique difficulties of the individual consumers in maintaining their work. It is indeed important as there are different perspectives between the caregivers and the consumers in the determinants hindering the job tenure (Hansson et al., 2003). To address this issue, it is necessary for them to have effective communication for promoting mutual understanding of the values of work (Boardman et al., 2002). Healthcare professionals in vocational rehabilitation team should therefore need to help the consumers and the caregivers initiate and continue conversation to look for a consensus of realistic

vocational goals together with the timeline, and then formulate the strategic plans accordingly. It can be achieved by two ways. Family psychoeducation should be provided to help the caregivers be more empathetic and considerate in attempting to reconcile conflicts arising in the process (Chien et al., 2007). Besides, ISE as a contemporary vocational rehabilitation program also plays a significant role. The caregivers should be engaged as partners with other ISE team members including psychiatrists, psychiatric nurses and occupational therapists to serve as facilitators throughout the vocational rehabilitation journey by, for instance, non-judgmentally exploring the consumers' job interests, more precisely assessing their work strengths and limitations, and sharpening their skills in solving problems and managing emotions (Yu et al., 2016). Nevertheless, there are challenges in providing vocational rehabilitation in China. The major one is the lack of well-trained occupational therapists in the mental health workforce (Li et al., 2015; Yip, 2007). Occupational therapy has been well recognized as a profession specialized in vocational rehabilitation for schizophrenia (Moll et al., 2003). The shortage of this group of professionals in the mainland, which may not be addressed easily in a short term, has been hindering the conceptualization and implementation of vocational rehabilitation interventions in the existing mental health services (Li et al., 2014b). More efforts have to be put to devise strategies to tackle such issues.

In this study, the high level of the perceived needs of psychosocial care in the unemployed consumers is probably associated with their low self-esteem. Unemployment is usually coupled with the experience of social discrimination that trims one's self-esteem through eroding the social status by hindering the access to remuneration and social networks (Panchanadeswaran & Dawson, 2011). Self-esteem is indeed one of the

significant components to be nurtured via psychosocial care (Gallagher & Monroe, 2006). This makes sense that the jobless consumers longed for some psychosocial care to help them boost their self-esteem. Interventions targeting at improving self-esteem should thus be needed, and cultivating self-acceptance is one of the effective ways. Self-acceptance is an important component of the psychological needs of people with schizophrenia in particular those who have long been stigmatized by and excluded from the society (Spaniol et al., 1999). Though difficult, it should be fostered during the recovery process. Recognizing the contribution of the consumers towards their recovery is the key to enhancing their self-acceptance through sensing self-worth, and having them engaged in making decision about their treatment options is one of the crucial means to achieve this goal (Tunner & Salzer, 2006). Ensuring informed choice is therefore necessary. The First Specialized Hospital of Harbin in northeastern China is an exemplar where the healthcare professionals facilitate the consumers and their caregivers to decide on the interventions by explaining the pros and cons of each choice (Larson et al., 2014). It should be highlighted that the treatment modalities for people with schizophrenia should not be confined to pharmacotherapy and hospitalization but also psychosocial interventions such as vocational rehabilitation (Meehan et al., 2007). Unfortunately, resources allocated to the latter are usually scarce. As a medical condition, it is of no surprise that persons with schizophrenia are allocated with healthcare resources for medical services including antipsychotics and hospital care. Unlike physical illnesses, the goals for those with schizophrenia however include not only objective recovery involving the alleviation of signs and symptoms but also subjective recovery focusing on the enhancement of social functioning (Sheridan et al., 2015). The latter can be achieved through vocational

rehabilitation by assisting the consumers to obtain and secure employment which is essential to their psychological wellness (Tsang & Chen, 2007; Yu et al., 2016). Nevertheless, this kind of psychosocial interventions is categorized under "non-health related" domain which receives very limited (if not none at all) allocation of healthcare resources (Cedereke & Ojehagen, 2007). This categorization has probably impeded the establishment and implementation of the vocational rehabilitation. To counteract this issue, it is worth reframing the domain of the related services. Instead of framing them as "non-health related" interventions, they should better be grouped under rehabilitation as they are basically the rehabilitation needs. Normally, certain amount of the healthcare resources is allocated for rehabilitation (irrespective of physical or psychiatric nature) in any countries (Putoto & Pegoraro, 2011). The allocation of the resources for vocational rehabilitation services as a type of rehabilitation interventions can hence be better justified.

3.3.4.1.2.2. BEHAVIOR AND IMPULSE CONTROL

The perceived importance of the factor “Behavior and impulse control” was significantly different between the regions and across the employment status respectively. The urban consumers had a higher level than the rural ones did. Those in sheltered workshop had the highest level and those unemployed had the lowest.

The difference between the urban and rural consumers in the perceived importance of the needs was probably related to the urge to conform to the social norms. In general, persons in societies with high value on collectivism usually have higher social conformity than those in the individualistic ones do (Triandis, 2001). China is such a

collective society and so the people generally tend to be more socially conformed (Wong, 2001). Higher level of social individuality usually exists in the urban regions where the diverse populations mean a great variety of cultures that people can quite freely choose from and adopt their own lifestyles without much restriction; rural people, on the other hand, are more homogeneous in their culture and social customs that any deviation from the norms is hardly tolerated by others in the community (Brehm & Kassin, 1996). Besides, owing to the small space in a village, all of the people around can easily note any deviated social behaviors. The consumers are thus in particular expected strictly by their family and the whole mini-community to comply with the social norms or otherwise blame will be placed to them and their family members (Donnermeyer, 1995). This kind of social pressure may have already forced the rural consumers to control their behaviors and impulse to an extent that they may simply perceive their acts as an obligation instead of a need. Although the people in the context of collectivism in China still have good subjective well-being, an increasing number of them tend to think that whether individualism may contribute more to their happiness and life satisfaction (Steele & Lynch, 2013).

In fact, sufficient and effective management of schizophrenia including adherence to pharmacotherapy and establishment of therapeutic relationship is the most suitable means to alleviate impulsive behaviors (Torrey, 2011). Impulsivity and aggression are associated with the abnormalities in the frontal and temporal lobes of the brain with the resulting psychotic symptoms including delusions and hallucinations which involve suspicion and hostility (Hoptman & Antonius, 2011). In addition to using antipsychotics and sedatives for adjusting the related biological mechanisms (Hughes & Kleespies,

2003), adopting psychosocial approach including expressing empathy and authenticity in the clinical contact should be able to build rapport with the individuals with schizophrenia, giving them the feeling of being understood and engaged, which in turn lessens their suspiciousness and agitation (Pompili & Fiorillo, 2015). Having auditory hallucinations can also be very annoying and stressful for the consumers. Their caregivers should try to develop a deeper understanding about their subjective voice experience by being more patient and empathetic in order to establish trust with them to work toward addressing the issues (Ng et al., 2012). Supporting the caregivers to help the hearers gradually realize that they can live well with the auditory hallucinations is probably useful for relieving their stress (So, 2008). More resources should thus be invested to formulate some culturally specific interventions for so with reference to the related well-developed psychoeducation programs in Hong Kong such as those from New Life Psychiatric Rehabilitation Association.

As for the employment status, the consumers in sheltered workshop had the highest level of the perceived importance in this factor and the unemployed had the lowest. This can be explained by their evaluation of self-efficacy. The ones in sheltered workshop may have encountered some troubles in relation to the poor control of their impulsivity and behaviors, or witnessed those occurred in their co-workers. They could thus realize clearly how severely the resulting acts such as quarrel or fighting affected their interpersonal relationships. They on one hand understood the criticality of proper behavioral and impulse control but could not manage it well on the other hand. They may therefore desire to receive some help for so. As for those unemployed, they may simply not have any chance to experience the impacts and thus may not perceive its importance.

They in turn need not evaluate their abilities in dealing with the related situations. While further research is warranted for verification, the healthcare professionals should focus more in the psychoeducation and other relevant interventions such as vocational rehabilitation on the ways to help the consumers of various job status better control their behaviors and impulsivity in the workplace. The WSST (Tsang & Pearson, 2001) may serve as a good reference for so.

3.3.4.2. PERCEIVED IMPORTANCE OF THE NEEDS IN CAREGIVERS OF PEOPLE WITH SCHIZOPHRENIA

3.3.4.2.1. PROFILE OF THE FACTORS

"Stress management" was ranked the highest among the eight factors. It is well in line with the international findings that taking caring of a relative with schizophrenia involves great commitment which puts the caregivers at immense psychological burden (Caqueo-Urizar et al., 2014). Such burden can be devastating when sacrifice of time, money, and prospects is involved (Mendez-Luck et al., 2008). The caregivers' stress is mainly induced by their struggle with something they have no ideas of or do not have enough support to deal with (Larson et al., 2014). For instance, the caregivers' job performance can be influenced by the caregiving due to the opportunity cost in balancing their own work and their care to the family members with schizophrenia (Haddock et al., 2006). Comparing with the co-workers who are non-caregivers, caregivers with a dual role in working and caring usually have more disturbances to their work such as taking more frequent time-off or day-off, having more worries about family matters, and feeling fatigued (Schulz et al., 2003). These issues are likely to result in a loss of productivity

and in turn impede their career advancement, and may eventually cause either resignation or even lay-off. The joblessness would then probably further worsen the financial conditions of the family in addition to the difficulties brought by the medical expenses for the consumer. It is worth conducting longitudinal studies to trace and verify the impact of caregiving burden on the caregivers' employment development. To alleviate the current situations, the financial challenges faced by the working caregivers in particular those younger ones who are in the golden period of developing their careers should be addressed by the related welfare policies and services which may otherwise further undermine their capacity and sustainability to provide the care (Lai, 2012). Advocacy together with employment policies is also needed to support the working caregivers by encouraging the employers to better accommodate the demands between their job duties and their caregiving responsibilities (Krach & Brooks, 1995).

Besides, an earlier study in the mainland (Zhang et al., 2014b) found that the caregivers of the consumers receiving combined medication and psychosocial interventions including psychoeducation, skills training, and cognitive behavioral therapy experienced less stress or burden comparing with those whose consumers had medication only. Although this combined mode is relatively more expensive, its favorable outcomes for both the consumers and the caregivers can well outweigh the additional costs. This overall further underscores the development of psychiatric rehabilitation in China.

In addition to this factor, "Caring skills" was another factor that was ranked over 4 by both the urban and rural caregivers. The desire of caregivers to be provided with assistance to enhance their skills in the caring process is indeed a clear indicator of the insufficiency of support in the existing mental healthcare system which may hence

account for their heavy psychological burden (Yeh et al., 2011). Caregivers should be recognized as the key persons for fostering socially inclusive environment for the consumers. Supportive environment created by caregivers is well recognized as a protective factor for people with schizophrenia by helping them enhance their social functioning but the ways to establish and maintain it have not been properly formulated (Tyrer & Bajaj, 2005). Unfortunately, the healthcare and social professionals in the mainland have not given due recognition to this contribution and thus the related support to the caregivers in need is scarce (Ran et al., 2005). The caregivers should be equipped with the knowledge and skills of care including the information on schizophrenia and its related medications, and the management strategies to handle difficult situations such as drug non-compliance and inappropriate social behaviors (Wallcraft et al., 2011). It is highly challenging for the caregivers to manage the consumers' medication non-adherence. In addition to the side-effects of antipsychotics and the consumers' poor insight about their illness, unsatisfactory therapeutic relationship between the healthcare professionals and the consumers can be the reason (Erol et al., 2015). As adherence assumes mutual agreement rather than following instructions as what compliance implies, consumers' medication adherence can be enhanced when they are engaged in the treatment decision as well as receive psychoeducation about the needs of taking medication and the ways to manage the side-effects (Fleischhacker et al., 2008; Tsang et al., 2016). This requires the collaboration between the professionals and the consumers. In this regard, advocacy groups have a role to play by overcoming the associated barriers such as the insufficient or improper communication between the healthcare professionals and the consumers. They should also explore the feasibility of empowering the caregivers

to contribute in the process by serving as a bridge to facilitate the communication and address the conflicts if any. The caregivers should be supported practically and emotionally through sharing in some peer support groups the difficulties in the caring process and the possible ways for handling them (Gun & Leong, 2016). Overall, in order to enhance the caregivers' self-efficacy in fulfilling their caring roles to promote the consumers' recovery, more efforts and resources should be put to enable the implementation of the aforementioned measures for the caregivers. This requires the collaboration between the government, policy makers, and various healthcare professionals especially on budget and manpower consideration with reference to the corresponding situations in the urban and rural regions.

3.3.4.2.2. DIFFERENCES WITH DEMOGRAHICS

In addition to the general concerns, significant differences across the demographic variables were noted in some factors.

Based on regression analyses, the hypotheses were supported that the factors "Security" and "Accommodation" predicted the caregivers in the urban or rural regions, and the age determined the scores in "Security".

3.3.4.2.2.1. SECURITY

The caregivers in different regions and of different age groups significantly differed in the perceived importance of the needs in the factor "Security". The urban ones had a higher level than the rural ones did. The oldest ones had the highest level and the youngest had the lowest.

The caregivers' emotional burden in the caring process is likely to affect their competency to fulfill the caring role and hence hinder the consumers' recovery. Particularly in Chinese societies, families are expected to take an active and major role in taking caring of the family member with mental illness as they value much the close family relationship under the influence of Confucianism whereas it is the healthcare system in the western countries which bears the main caring responsibility (Park et al., 2005). The caregiving burden is probably heavier when a caregiver perceives the caregiving role as a threatening obligation (van den Wijngaart et al., 2007). While the extent of such burden varies with the socio-economic feature between the urban and rural regions in the mainland, a lack of community support in either region may complicate the caring process. In this study, the urban caregivers had a higher level of the perceived importance in the factor "Security" than the rural ones did. It can be explained by the nature of urban life and the quality of social relationship with the caregivers. The fast moving, competitive and hectic life together with the weak and superficial social relationship in the urban areas is likely to induce insecurity to the caregivers (Beggs et al., 2006) which is worsened by the poor community support system (Mueller et al., 2006). It is therefore urgent to support the caregivers emotionally by strengthening the mental health system to enable the provision of socio-culturally specific interventions to duly tackle the challenges (Flisher et al., 2007) such as the struggle to balance between their own job and the caring tasks. The caregivers should thus be catered with comprehensive psychoeducation which does not only guide them how to support the consumers but also help them identify and evaluate their own coping strategies (such as emotion-focused and problem-focused) for handling the daily issues in order to fine-tune the ways to manage

their stress more effectively (Chadda, 2014).

In addition to the nature of urban life and the quality of caregivers' social relationship, stigma is a critical factor that deserves attention. The caregivers of people with schizophrenia in China experience moderate to severe degree of stigma (Fung et al., 2011; Phillips et al., 2002). Persons with schizophrenia reported that their illness made their caregivers be treated unfairly, and the situations were so devastating that both parties tended to conceal their relationship (Lee et al., 2005). In fact, a number of social-demographic factors correlate with stigma. Stigma is more severe in the urban regions than the rural ones (Girma et al., 2014). This can explain why the urban caregivers in this study perceived a higher level of the needs in security. Comparing with the rural areas, the large increase in the competitiveness in the urban job market because of the rapid industrialization has created challenges for workers who are less skilled or insufficiently trained to meet the demands for high efficacy in performing work duties (Johnson et al., 2002). This may make the persons with schizophrenia in particular those who have lower vocational competencies hard return to the workplace and fail to resume a meaningful worker role and hence social role. Their unprivileged social status is likely to elicit serious public stigma (Pescosolido et al., 2015) and the resulting social exclusion may further induce difficulties in job seeking. These experiences of stigma can undermine the caregivers' psychological security by inducing stress and burdens (Larson & Corrigan, 2008; Meyer, 2003). It is because the caregivers in particular those in Chinese societies are obligated to help the family members optimize their prospects (Malhotra & Sachdeva, 2005) and failure to assist them to get a job can be blamed as non-fulfillment of the caring role (Garey & Arendell, 1999). Besides, caregivers aged over 45 usually perceive

a higher level of stigma (Shibre et al., 2001) probably due to the shrinking social support. Normally, a person's social network will become narrower when he gets older and so will the social support (Charles & Carstensen, 2010). As social support is useful for mediating the caregivers' perception of stigma (Mueller et al., 2006), the reduction in social support with age may mean a weakening of their ability to counteract the impact caused by the stigma and in turn make them feel less secured. This can explain why the oldest caregivers in this study had the highest level of the perceived importance in security. The Chinese government should address the public stigma on mental illness by putting this agenda into the mental health policy, and implementing the corresponding measures such as anti-stigma campaigns to alleviate the stereotype agreement in the society that all people with schizophrenia are horrible such as being violent and dangerous (Fung et al., 2007). Cost-effectiveness of these campaigns should be evaluated timely as they may be costly but their outcomes may not be prominent (Li et al., 2013b). Besides, more community services for the caregivers should be provided which target at emotional support for managing their stress and promoting their psychological wellness (Sin & Norman, 2013). These measures need the collaborative efforts by the government, policy makers and various healthcare professionals so that more financial and human resources may become available. In developing countries like China where insufficiency in resources for mental health is common, advocacy coupled with cost-effectiveness research should be effective to overcome the barriers to the development and implementation of mental health services. Advocacy aims to reach the upper level of the government to lobby for a higher priority of mental healthcare in the health policy (World Health Organization, 2005). It can be supported by the findings from cost-effectiveness

studies to serve as evidence to fight for more resources for the mental health interventions. There is an evidence-based intervention adopting peer-to-peer model targeting to train up caregivers to be a supporter for other caregivers (Repper & Carter, 2011). It is probably cost-effective as the training may not be costly but the impacts can be powerful. In fact, this approach pinpoints the significant predictors of insecurity in Chinese caregivers including limited social support, poor communication skills and insufficient knowledge (Zeng et al., 2016). It is a comprehensive model of psychoeducation with a combination of provision of information, skills and support. Knowledge about mental illness and the management modalities is instilled to the caregivers in the beginning followed by some practical skills such as the strategies to communicate with the consumers, and finally mutual support to enhance the emotional capacity in coping (Bhattacharjee et al., 2011). For instance, caregivers should be strengthened with the knowledge about the behavioral characteristics of the consumers as well as the nature of the related behavioral issues such as poor motivation in performing daily tasks, and hence the corresponding management strategies. They should also consider joining mutual-help group to receive peer support for relieving negative emotions through sharing their experiences and feelings in the caring process. These kinds of support can promote caregivers' resilience and hence sense of security (Amagai et al., 2016). Research findings in overseas indicate that the rates of relapse and hospitalization can be decreased by 20% when family caregivers are properly empowered and supported to be engaged in the psychosocial rehabilitation process (Pitschel-Walz, 2001). More resources should be invested in mainland China to implement this kind of psychosocial interventions specific to the regions and the age groups of the caregivers, and evaluate the effectiveness.

3.3.4.2.2.2. ACCOMMODATION

The levels of the perceived importance in the factor “Accommodation” significantly differed between the regions with the urban caregivers being higher than the rural ones.

It is quite common that persons with mental illness face problems of homelessness (Lloyd & Bassett, 2012). In fact, proper housing is essential for creating a supportive environment through establishing productive social network, and psychological wellness (Tyrer & Bajaj, 2005). Enabling housing for the individuals with schizophrenia is a key to reducing the disability and impairment experienced by them (Croft, 2016). In contrast, unsatisfactory accommodation deters recovery and probably results in prolonged hospitalization (Tulloch et al., 2012), social isolation (Stergiopoulos et al., 2015), suicide, and violence (Kooyman et al., 2007). The caregivers in both regions did not perceive the needs of accommodation as highly important probably because of the availability of enough living places in the mainland. The higher means in the urban caregivers may simply be because of the relatively smaller space available in the urban areas as compared to that in the rural areas. Further exploration is needed for verifying this geographical factor. Despite this, the caregivers in both regions may not realize the values of good housing in facilitating recovery through promoting mental wellness and community integration. Policy makers should thus mobilize the efforts of the healthcare professionals, social care professionals, caregivers, and citizens to cultivate supportive and harmonious atmosphere in the communities to facilitate social inclusion of the persons with schizophrenia.

3.3.5. IMPLICATIONS OF FINDINGS

Almost all of the factors of the rehabilitation needs found to be significant in this study are psychosocial in nature. It is reasonable to suggest that psychosocial rehabilitation should urgently be provided to help the individuals with schizophrenia and their caregivers better satisfy their needs in the corresponding domains. Unfortunately, as discussed in Chapter Two, there is room for the concepts and practices of psychosocial rehabilitation in China to be fostered that the use of psychosocial interventions in the management of schizophrenia should be given better recognition. Such kinds of issues have also been reflected by the respondents of the qualitative study in Phase Two. With the findings systematically yielded by the studies using both quantitative and qualitative approaches in this research, the allocation of healthcare resources for implementing psychosocial rehabilitation for schizophrenia may be justified more strongly. It is of utmost importance as the supply of services to all in need is the pre-requisite of alleviation of health inequalities (World Health Organization, 2008). Despite that the healthcare resources may not be supplied to the services for mental illnesses as sufficiently as those to physical illnesses, the expenditure for mental health care should be clearly listed in the fiscal budget in the provincial level down to the municipal level to help match the allocation of the resources with the corresponding demands (Xiong & Phillips, 2016). Moreover, the quality of the services is also a critical determinant (Tateke et al., 2012). It is worth taking the good work done in Chinese societies as references. The development of psychiatric services in Hong Kong (its socio-economic features are similar to those of Wuxi) is on enhancing the quality of community-based services including preventive and restorative mental health interventions (Tsang, 2011) which are

more holistic and humanistic (Cheng, 2011). In Hong Kong, for instance, the Integrated Community Centers for Mental Wellness serve to provide the individuals with mental health issues and their caregivers in community with psychosocial support and rehabilitation services through the one-stop district-based integrated service mode (Social Welfare Department, 2017). Besides, some organizations in Singapore aim to tackle the stigma by improving the mental health literacy and positivity of the public through, for example, organizing monthly community mental health promotion campaigns to reach out the various groups of the population (Trivedi et al., 2014). To have a clearer understanding of the directions for improvement in China, it is worthy to further investigate the factors affecting the quality of primary care provided by the community settings, and review the medical insurance policies to enhance the financial feasibility of quality primary care services (Zeng et al., 2015). The emphasis should be on the mobilization and connection of the political actions, the integration of medical, psychological and social interventions, and the commitment of the stakeholders as this synergy is central to enhancing the quality of care of individuals with schizophrenia and their caregivers (Fleischhacker et al., 2008). It should be desirable to facilitate public policy making by facilitating intersectoral collaboration among healthcare system, financial system, social security system, insurance system, education system and labor system (World Health Organization, 2008). In this regard, more resources should be invested on health policy and systems research in China. This kind of studies should be able to help the societies better utilize their unique capacities to attain health goals through lining up all of the stakeholders to cooperate in the policy making and implementation process to optimize the policy outcomes, and also to facilitate the

reciprocal interaction between health policies and health systems such as how the policies shape or are shaped by the systems, and how well the systems react to the policies (World Health Organization, 2017). The findings may therefore serve as useful references for both the policy makers in Wuxi and the mental health experts in places with similar socio-cultural background such as Hong Kong to provide the frontline healthcare professionals with some useful ideas as to how to more precisely develop the culturally relevant and regionally specific services to help maximize the benefits to the people with schizophrenia and their caregivers.

3.3.6. LIMITATIONS

The recruitment of the participants by convenience sampling from a single site where they received services might have affected the external validity of the results. This familiar environment might on the other hand have let the participants feel comfortable to respond to the questions in the measurement tools and thus help enhance the trustworthiness of the ratings (Tunner & Salzer, 2006). Nonetheless, cautions should be made when generalizing the findings to the formulation of the related policies and services in mental health. To enhance the generalizability, it is worth conducting further quantitative studies with subjects recruited from various sites through random sampling.

3.4. TRIANGULATION

There is a triangulation of the rehabilitation needs between the qualitative studies in Phase Two and the quantitative studies in Phase Three. The following is the table summarizing the contents.

Table 14
Triangulation of the rehabilitation needs between the qualitative studies and the quantitative studies

	Qualitative studies	Quantitative studies
People with schizophrenia	Community rehabilitation not sufficiently received	The importance of the needs of community rehabilitation rated high
	Being discriminated when seeking employment	The importance of the needs of psychosocial care rated high; for tackling erosion of self-esteem due to unemployment
	Poor control of mental conditions regarded as a major barrier of employment	The importance of the needs of symptom management rated high
Caregivers	Community care not sufficiently received	The importance of the needs of caring skills rated high
	Support in the caring process not sufficiently received	The importance of the needs of social support rated high
	Management of caregivers' emotions regarded as important	The importance of the needs of stress management rated high

CHAPTER 4 POLICY RECOMMENDATION

4.1. POLICY IMPLICATIONS

There are a number of policy implications from the three phases of this study. Improvement in economics and literacy in a society usually increases the citizens' expectations towards health and healthcare systems despite that some are realistic while the others are self-serving (World Health organization, 2008). It is reasonable to develop health policies and tailor services to satisfy the unique and ever changing rehabilitation needs of the main service users including the people with schizophrenia and their caregivers. Both conceptual and practical approaches have to be focused in which healthcare policy commitments are necessary.

4.1.1. CONCEPTUALIZATION OF PSYCHOSOCIAL REHABILITATION

Conceptually, the nature of psychosocial rehabilitation should be clearly delineated. As psychosocial rehabilitation focuses on "doing with" instead of "doing for" or "doing to" the persons with mental illness, it should aim at empowering them and their caregivers to transform helplessness and powerlessness into challenges and opportunities by reframing the problems facing them into the manageable issues (Mathew, 2016). With more sufficient time and professional workforce, holistic rehabilitation care embedding physiological, psychological, social, and spiritual aspects can be more easily achieved in community care than in hospital care. This mode of care is more humanistic as it can maintain the consumers' contact with their family and other significant people in their social network, which is largely restricted if hospitalized (World Health Organization, 2008). It is thus very likely to lead to more favorable outcomes including better quality of

life. Policy makers have to be aware of these potential benefits from the points of views of health economics when allocating resources between hospital sectors and community sectors. Agreeing with Xiong and Phillips (2016), in addition to exploring the feasibility of adopting the purchase mode to encourage non-governmental organizations to develop community-based psychiatric rehabilitation services, the relevant stakeholders and advocacy groups should look for ways to synergize the multiple insurance systems including the Basic Healthcare Insurance, the Critical Illness Insurance Program for Urban and Rural Residents, Medical Aid, and Medical Emergency Aid to strengthen the healthcare security for the individuals with schizophrenia in particular those living in the rural regions. Besides, recovery reciprocally correlates with social inclusion that it requires and enables social inclusion, and social inclusion promotes it (Boardman, 2010). Recovery pertains to discovering or re-discovering the meaning of life (Andresen et al., 2003) and satisfying the valued social roles through social inclusion is central to its success (Shepherd et al., 2008). Social exclusion commonly exists in people with mental illness in which they are prohibited from participating in activities in the community necessary for fulfilling the expected social roles such as employment due to various unfavorable factors including discrimination (Boardman, 2010). It is hence worthy for the mental health policy makers to consider facilitating the collaboration between the labor department and the employment sectors to educate the employers and employees about the importance of work in the recovery of people with mental illness, and how to support them appropriately in the workplace (World Health Organization, 2005). Advocacy for modifying employment policies is also needed to assist the working caregivers by encouraging the employers to better accommodate the demands between their job duties

and their caregiving responsibilities (Krach & Brooks, 1995).

4.1.2. IMPLEMENTATION OF PSYCHOSOCIAL REHABILITATION

In practice, a number of indicators of recovery in the interventions adopting recovery-oriented approach such as employment, financial independency, cordial family relationship, social harmony, self-management, and life satisfaction drive the directions of the services contributing to social inclusion (Liberman & Kopelowicz, 2002). With better financial support under the mental health policies, the manpower of the inter-disciplinary psychiatric team can be enriched which can allow the related services to facilitate social inclusion and make resources more widely available and more sustainable. They include the assessment of the consumers' social roles (such as family role, worker role, peer role, citizen role) and the extent of their fulfillment, and the provision of the interventions such as vocational rehabilitation for assisting them in job seeking and maintenance, family psychoeducation for appropriate support to them, and community education for anti-stigma of mental illness (Killaspy, 2014). Furthermore, it is worth empowering the consumers and caregivers to be engaged in policy making by establishing advocacy groups to lobby for the directions of and the associated resources for the service formulation and provision (Wallcraft et al., 2011).

4.1.3. POLICY RECOMMENDATIONS

The healthcare policy makers and health administrators in the mainland should endeavor to facilitate the implementation of the following measures to benefit the consumers and caregivers in the urban and rural areas of Wuxi:

1. Fostering the public and people in the health and social care fields the concepts of recovery and psychosocial rehabilitation for schizophrenia
2. Recognizing and satisfying the unique rehabilitation needs perceived by the consumers and caregivers
3. Nurturing inter-disciplinary alliance in psychiatric rehabilitation through increasing the manpower of the team (in particular rehabilitation practitioners such as occupational therapists) and fostering the conceptual understanding on the views of recovery and the operational co-operation in the corresponding interventions
4. Encouraging collaboration between the provincial government and the non-governmental organizations in catering financially viable and sustainable community psychiatric rehabilitation services
5. Increasing subsidies for medical expenses through the expansion of insurance coverage by synergizing the multiple insurance systems, and through the procurement of cost-effective anti-psychotics
6. Providing evidence-based vocational rehabilitation programs such as ISE for the consumers to enhance their employability and tenure, with due engagement with the caregivers and the employers
7. Strengthening stress management programs for the caregivers through tailoring psychological interventions such as psychoeducation, counseling, and peer support groups, and instrumental input such as financial support, caring skills, and respite
8. Offering evidence-based anti-stigma programs for the public, and self-stigma reduction programs for the consumers
9. Creating socially inclusive and supportive environment to promote the community

re-integration of the consumers and the social harmony

10. Improving the mental health literacy of the public for better awareness and expression of their needs in mental health care

4.1.4. THE WAY FORWARD

The findings from the three phases of this study may be useful for the related organizations such as the China Disabled Persons' Federation on the ways to develop culturally specific psychosocial rehabilitation services for the persons with schizophrenia through coordinating, mobilizing and synergizing the financial and human resources within and outside the mainland. The monetary input may include regular healthcare budgets from the central and provincial governments, various insurance plans, funding from donors, and even sponsorship from companies. To address the manpower shortage issues, inviting experts and recruiting front-line professionals in psychiatric rehabilitation from other Chinese societies such as Hong Kong and Taiwan for giving directions and providing interventions respectively is likely to be a short-term solution. Training the related professionals by local tertiary institutions is probably the way out in the long run. It is encouraging to note that the first rehabilitation university will be founded by 2020 under the latest Five-Year Plan of China (China Daily, 2016). It should be a good opportunity to gather the psychiatric rehabilitation scholars around the world to tailor make the corresponding teaching programs to equip the new breeds of workforce with the knowledge and skills necessary for launching the holistic rehabilitation services in accord with the contemporary modes. Besides, this university may also serve as a platform for inter-country collaboration in conducting comparative health policy research in areas

such as health economics to explore the ways to translate policies into practice, and clinical research to investigate the effectiveness of interventions such as vocational rehabilitation programs. The findings may be conducive to nurturing the evidence-based practice of psychiatric rehabilitation in China. It may then help satisfy the perceived rehabilitation needs of the people with schizophrenia and their caregivers, and in turn maximize their quality of life.

CHAPTER 5 CONCLUSION

The PRNQ-S-WX and PRNQ-C-WX have been validated in Wuxi based on the original versions developed in Hong Kong. These two standardized questionnaires can be regarded as the first of its kinds in China which can scientifically measure the perceived rehabilitation needs of the two major stakeholders, namely, individuals with schizophrenia and their caregivers, in Wuxi, and across other regions in the mainland upon further validation. The qualitative study adopting semi-structured individual face-to-face interviews has been conducted to help deepen the understanding on the two stakeholders' awareness and evaluation on the psychiatric rehabilitation policies and services in the urban and rural regions of Wuxi. It attempted as a triangulation to the quantitative survey using the two standardized measurement tools respectively to facilitate more thorough investigation and comparison of their rehabilitation needs regionally, and thus the review of the current psychiatric rehabilitation development in Wuxi. The central and provincial governments may find the findings of the studies from the three phases useful for assisting to formulate or fine-tune the mental health policies and strategies to tailor needs-driven psychiatric rehabilitation interventions. This may then be conducive to satisfying the corresponding rehabilitation needs of the people with schizophrenia and their caregivers in Wuxi, and thus help alleviate the associated immense humanistic and economic burdens and in turn maximize their quality of life. Upon careful consideration of some potential socio-cultural differences, the findings may also serve as valid references for the policy makers, administrators, researchers and clinicians in the related fields in other regions of China to promote evidence-based practices in the psychiatric rehabilitation for schizophrenia.

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