JOB REFUSAL AMONG PEOPLE WITH SCHIZOPHRENIA IN HOSPITAL PERMAI, JOHOR BAHRU

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DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTERS IN PSYCHOLOGICAL MEDICINE

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ABSTRACT

Title

Job Refusal among Patients with Schizophrenia in Hospital Permai, Johor Bahru.

Background

The goals for treating patients with schizophrenia are now not only limited to symptoms reduction and relapse prevention. Functional recovery is equal, if not the most, important in treating patients with schizophrenia. Functional recovery encompassed: symptoms stability, independent living, work functioning and social functioning.

Method

This study uses Explanatory Sequential Mixed-method design. It involved both quantitative and qualitative statistical analysis. In the first part, the quantitative approach, 96 people with schizophrenia referred to Hospital Permai's OT for supported employment were assessed quantitatively for employment characteristics (duration of employment, the number of previous jobs and longest job) and clinical characteristics using RSES (Rosenberg self-esteem scale), QUAD (Questionnaires on Anticipated Discrimination), PANSS (Positive and Negative Symptoms Scale), and GASS (Glassgow Antipsychotic side effect scale). In the second part, the qualitative approach, thematic analysis of from nine individual interviews and two focus groups interviews consisting of thirteen employment specialists were carried out. The results and findings from these two parts were integrated and interpreted together.

Result and Findings

From the Part 1 of the study, the prevalence of people with Schizophrenia that refused to work after referral to the Supported Employment program is 24.0%. The study also found a significant association between 'Duration of unemployment' and 'Job refusal' with P=0.031, OR =1.018 (95% CI=1.002 - 1.035). Part 2 of the study identified several themes related to job refusal among people with schizophrenia namely; Cognitive Deficit Secondary to Schizophrenia, Side Effects of Medications, Easily Contented, Lack of Drive, Stigma (Internal and External), Subpar Work Performance, Fear of Relapse, Somatic Symptoms, Inadequate Social Skills, Dependency on Family, Family as a Barrier, Stigma from healthcare professionals, stigma from employers, and Stigma from community.

The mixed method employed by this study found that the reasons for job refusal are related to anxiety. This anxiety could have been heightened by the long duration of unemployment. Our study also postulates that these anxieties are caused by poor work performance secondary to cognitive deficit associated with schizophrenia, inadequate social skills, and internalized stigma and stigma from general population. We also found that the patients' family may also act as a barrier to employment by being over-involved in patients' illness.

Conclusion

All in all, there should be close collaboration between all the services in mental health service, with focus on psycho-education and increasing contact between community and people with mental illness to help them to manage themselves better to return to function. We should focus not only on symptoms remission, but to start managing them holistically and aim for functional recovery.

ABSTRAK

Latar belakang

Matlamat untuk merawat pesakit skizofrenia kini tidak lagi terhad kepada pengurangan gejala dan pencegahan penyakit berulang. Pemulihan fungsi (Functional recovery) adalah sama penting dalam merawat pesakit skizofrenia. Pemulihan fungsi (Functional recovery) meliputi: kestabilan simptom, hidup berdikari, fungsi kerja serta fungsi social.

Kaedah

Kajian ini menggunakan reka bentuk Penjelasan Sequential bercampur-kaedah (Explanatory Sequential Mixed-Method Design). Ia melibatkan kedua-dua analisis statistik kuantitatif dan kualitatif. Dalam fasa kajian pertama, pendekatan kuantitatif, 96 pesakit dengan skizofrenia yang dirujuk ke Hospital Permai OT untuk 'Supported Employment' dinilai secara kuantitatif untuk ciri-ciri pekerjaan (tempoh pekerjaan, bilangan pekerjaan sebelumnya dan kerja paling lama) dan ciri-ciri klinikal dengan menggunakan skala harga diri RSES (Rosenberg self-esteem scale), skala diskrimininasi QUAD (Questionnaires on Anticipated Discrimination), gejala Schizophrenia PANSS (Positive and Negative Symptoms Scale), dan skala kesan sampingan ubat-ubatan GASS (Glassgow Antipsychotic side effect scale). Dalam fasa kajian kedua, pendekatan kualitatif, analisis tematik daripada temu bual individu dan temu bual kumpulan fokus telah dilakukan. Keputusan dan penemuan daripada dua bahagian ini akan diintegrasikan dan ditafsirkan bersama-sama.

Hasil kajian

Hasil daripada Fasa kajian pertama, mendapati hubungan yang signifikan antara 'Tempoh pengangguran' dan 'keengganan bekerja' dengan P = 0.031, OR = 1,018 (95% CI = 1,002-

1,035). Fasa Kajian kedua ini telah mengenalpasti beberapa tema yang berkaitan dengan keengganan untuk bekerja di kalangan orang-orang dengan skizofrenia iaitu; Defisit Kognitif yang disebabkan oleh penyakit Skizofrenia, Kesan Sampingan Ubat-ubatan, mudah berpuas hati, Kekurangan motivasi, Stigma (Dalaman dan Luaran), Pencapaian Kerja subpar, Takut Relapse, Gejala somatik, Kemahiran sosial yang tidak mencukupi, Kebergantungan kepada keluarga, keluarga sebagai penghalang stigma daripada golongan professional kesihatan, stigma daripada majikan serta stigma dari komuniti.

Fasa kajian kedua ini mendapati bahawa sebab-sebab bagi penolakan pekerjaan berkaitan dengan kebimbangan. Kebimbangan itu telah bertambah teruk disebabkan oleh tempoh yang panjang pengangguran. Kajian kami juga mengandaikan bahawa kebimbangan ini adalah disebabkan oleh prestasi kerja yang lemah disebabkan oleh defisit kognitif yang berkaitan dengan penyakit skizofrenia, kemahiran sosial yang tidak mencukupi, stigma dialami serta stigma dari populasi. Kita juga mendapati bahawa keluarga pesakit juga boleh bertindak sebagai penghalang kepada pekerjaan dimana mereka terlebih-penglibatan dalam pengurusan penyakit pesakit.

Kesimpulan

Oleh itu, perlulah ada kerjasama erat antara semua perkhidmatan dalam perkhidmatan kesihatan mental, dengan tumpuan kepada psiko-pendidikan dan meningkatkan hubungan antara masyarakat dengan orang-orang dengan berpenyakit mental. Ini adalah untuk membantu mereka untuk menguruskan diri mereka lebih baik supaya dapat kembali berfungsi. Kami perlu memberi tumpuan bukan sahaja kepada pengurangan gejala-gejala Skizofrenia, tetapi juga dalam pengurusan penyakit mereka secara menyeluruh dan dengan matlamat pemulihan fungsi (functional recovery).

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IPS	Individual Placement and Support
SE	Supported Employment
ES	Employment Specialist
JB	Johor Bahru
OKU	Orang Kurang Upaya
FGI	Focus Group Interview
RSES	Rosenberg Self-esteem Scale
QUAD	Questionnaire of Anticipated Discrimination
GASS	Glasgow Antipsychotic Side-effect Scale
PANSS	Positive and Negative Symptoms Scale

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CHAPTER 1

INTRODUCTION

Traditionally, healthcare professional focused on treating the symptoms of schizophrenia and trying to cure it. Hence, along the way, they 'forgot' to treat them as a whole, neglecting the social importance (Boardman, Grove et al. 2003). As we began to understand more about Schizophrenia, the goals for treating patients with schizophrenia are not only limited to symptoms reduction and relapse prevention. Functional recovery is equal, if not the most, important in treating patients with schizophrenia. Functional recovery encompassed: symptoms stability, independent living, work functioning, as well as social functioning (Kern, Glynn et al. 2009).

In view of the importance, psychiatric rehabilitation has become the major component in the management of patients with schizophrenia. This includes vocational rehabilitation with the objective to help patients return to work. Over the years, there had been many types of vocational rehabilitation programs being developed and implemented. They are classified as follows (Bond and Boyer 1988, Ciardiello and Bell 1988): (1) hospital-based programs; (2) sheltered work; (3) assertive case management; (4) psychosocial rehabilitation, including prevocational training, transitional employment, and volunteer placements; (5) supported employment; and (6) counselling and education.

Hospital Permai, Johor Bahru is the second largest mental institution in Malaysia. Besides offering a wide range of services, it also actively runs vocational rehabilitation for patients, helping them to regain functionality. However, over the years, it has progressed from traditional rehabilitation i.e. the 'train-and-place' model to the current model of

Individual Placement and Support (IPS) Supported Employment. Traditionally, vocational rehabilitation employed 'Train and Place' Model, where they acknowledge the patient's deficit related to their illness, for example, cognitive impairment in Schizophrenia and Intellectual disability. They involve placing patients in a gradual stepwise training over periods of months and some even years. Patients often began with pre-vocational training in groups, followed by assessments and finally placing the patients in a customized employment. Unpaid positions and forms of sheltered employment were considered helpful to prepare people for competitive employment in the open labour market (Bond and Boyer 1988). The Occupation therapists are often the one in charge to train these patients and prepare them to return to employment. However, this approach has proven little success in helping the patients to gain employment competitively outside a mental institution. As a result, most of these patients end up working only in sheltered environments or sometimes known as 'pre-vocational programs'. Examples of these 'training' or 'pre-vocational programs' includes agriculture, carpentry, handicrafts, and many other simpler tasks such as packaging. But all these programs are confined inside the mental hospital, which continues to deprive patients of social contacts, ie 'social poverty'. Wing and Brown (1970) had shown how 'social poverty' in the large mental hospital may lead to 'clinical poverty' (Wing and Brown 1970).

Vocational rehabilitation of individuals with severe mental illness continues to become the focus of serious attention at the end of the 20th century (Cook and Jonikas 1996). Over the last two decades, new evidence has emerged. This evidence, mainly studies done in the USA, showed that it is more beneficial for the patients to be placed in a competitive job and then trained with supports (the opposite of traditional Vocational Rehabilitation) (Bond 2004, Bond, Drake et al. 2008). This revolutionized Vocational Rehabilitation is also known as 'Individual Placement and Support (IPS) or Supported Employment'.

In July 2009, Hospital Permai, Johor Bahru, started to adopt (Individual Placement and Support) IPS Supported Employment Program. It is operated by a group of Occupational Therapist who are trained to become Job Coaches and later known as Employment Specialists (ES). It started off with 8 Job Coaches to currently 18 Employment Specialist. Abiding by the principles of IPS, the Employment Specialists focuses on patients' strength and helps them to be employed according to jobs of their choice. There are 'no exclusion criteria' fixed for the patients to enter this program. So long, they express interest to work, regardless of diagnosis, past criminal history, history of substance use and family background, they will be included in this program and the ES will support them to obtain competitive jobs according to their preferences within the shortest period. Although managed solely by Employment Specialist, they worked closely with other teams such as Community Psychiatry Units, Outpatient Departments, as well as Social Welfare Department. Together with these teams, ES will also help them to gain any social welfare benefits which they are entitled to such as 'OKU card' or 'Elaun Pekerjaan Cacat' (EPC). The ES also helped to make sure that the patients have proper follow ups with either Community Psychiatry Teams or at the Outpatients Department. When the patients are employed, the ES will also provide education and support to the patients' employers. The ES will engage with the employers and educate them not only about people with mental illness but also regarding the benefit of employing their clients such as 'tax reduction' and 'financial reimbursement' provided by Social Welfare Department and Inland Revenue Board of Malaysia. This will help the employer to gain confidence in hiring this group of patients and also this will also help the patient to sustain longer in their jobs. The services provided by IPS supported employment have no expiration, they will continue to support and aid the patients so long they want it and needs it. Further research also showed that IPS Supported Employment improves in employment commencement as well as the duration of employment (Bond 2004, Cook, Lehman et al.

2005, Bond, Drake et al. 2008). A more recent study also showed that IPS supported employment model is identified as the most effective way to support people with schizophrenia to work (Taskila, Steadman et al. 2014).

In fact, in this study, the two groups of patients are compared, that is, those working under IPS Supported employment versus those refused to work. However despite adequate staff, they sometimes find it difficult to attain and sustain a job for the patients. And there is a significant portion of them that refused to work direct or indirectly. Unfortunately, limited studies to date look into reasons why patient refused to work. Most studies are looking into the reasons or associated factors for unemployment and job termination in patients with schizophrenia. To date, no local research has been done to investigate the reasons for job refusal or exploring why patients with Schizophrenia rejected employment. Besides, the differences in the welfare system, family supports, and dynamics, diversity in race, religion and culture as well as economic needs and structure in Malaysia might have different findings than studies which had already done outside Malaysia. Consequently, there is a need for such study to be carried out to explore the reasons behind job refusal for a certain group of patients.

1.1 Definitions

'Work' is defined by Oxford Dictionary as 'Activity involving mental or physical effort done in order to achieve a result' (Simpson and Weiner 1989). Traditional definitions of work emphasize that it is an activity involving the execution of skills and application of judgement taking place within set limits prescribed by others (Bennett 1970). In other words, it is something you do for other people. 'Job' or 'employment' is defined as work you get paid for (Boardman, Grove et al. 2003). Economist and most people in society view employment as an opportunity to make money simply to provide purchasing power. In contrast, psychology and sociology emphasize the centrality of work to individual well-being (Gill 1999). Indeed, as mentioned earlier, employment has many benefits.

Employment not only provides financially but it also provides non-financial gains to the employee; which include social identity and status; social contacts and support; a means of structuring and occupying time; activity and involvement; and a sense of personal achievement (Shepherd 1989). Even with so many known benefits of employment, it is puzzling why people, especially people with schizophrenia, are largely unemployed. Was it because they are not able to work, refused to work or both?

'Refusal of work' is defined as 'behavior which refuses to adapt to regular employment' (Berardi 2003) and/or 'the state of avoiding or not wanting to work or be employed' (Berardi 2003). Most studies focused on barriers or reasons for unemployment for people with schizophrenia. It is not exactly known if the people with schizophrenia are unable to work or refusing to work and thus the need for this research to fill in the 'gap'.

Our Malaysia Mental Health Registry recorded unemployment (never employed or unemployed) rate of people with Schizophrenia as high as 63-66% (Aziz, Salina et al. 2008). The rate is similar to what was reported by an Australian population survey of people with psychotic disorders, where only 16% of people with schizophrenia, and 27% of people with bipolar affective disorders, were employed (Waghorn, Chant et al. 2007). Similar rates were also reported in other countries such as the United Kingdom, the United States of America. This is worrying as it shows that many are yet to be done in helping these groups of patients to gain functionality. NMHR 2003-2005 also quoted that 'The severity of illness among inpatient may be the reason for their admission and inability to obtain and sustain employment.' (Aziz, Salina et al. 2008). This will be one of the areas this study will be exploring; reasons for job refusal among people with Schizophrenia.

CHAPTER 2

LITERATURE REVIEW

Literature review goes to look at the prevalence and rate of unemployment among people with schizophrenia. It will also look at the how schizophrenia progress and its course and what we had known about it so far especially in the way we manage people with schizophrenia. Functional recovery as the main bulk of management for schizophrenia and benefits of employments will also be looked into. And finally literature review will attempt to explore what we had known about barriers to unemployment locally and internationally.

2.1 Prevalence

According to Department of Statistics, Malaysia, in 2014, Malaysia estimated a total population of 30.6 million. The unemployment rate for the general population in that same year was recorded at 2.9% (Jabatan perangkaan malaysia). The average employment rate for the general population is 67.6% with the male employment rate of 80.8% and female employment rate 53.4%. In contrast, the incidence rate reported in the paper published in 2008 by NMHR for schizophrenia was 7.7 - 43.0 per 100,000 population. The unemployment rate was reported to be as high as 70% (Abdul Aziz 2007, Aziz, Salina et al. 2008). These two data clearly showed that a high proportion of people with schizophrenia are not employed when compared to general populations. The low employment rate in people with schizophrenia not only showed that majority of patients failed to achieve functional recovery (Kern, Glynn et al. 2009), but it also becomes a burden to the country's expenditure. A study by Wu EQ 2005 in the USA estimated that

the productivity loss due to the illness schizophrenia took up 50% of the total cost associated with schizophrenia (Wu, Birnbaum et al. 2005). According to WHO, Mental illness is developed countries is second leading burden of disease. And it is estimated that the numbers are still rising and might overtake ischaemic disease as world's leading burden of disease in term of the economy lost and disability-adjusted life year (DALY) (Murray, Lopez et al. 2001). Our own local statistics by Institute of Public Health, Malaysia also showed the similar trend.

Comparing the employment among the 'disabled group', people with schizophrenia has one of the highest unemployment rates among all vocationally disabled groups (Marwaha and Johnson 2004, Kilian and Becker 2007). According to the UK national statistic, only 18% of people with mental disabilities were in employment, compared to 52% for people with disabilities but no mental difficulty. A large study by Haro et al., 2011, which combined data from 37 different countries also found that on average 19% of people diagnosed with schizophrenia were in paid employment, with figures ranging from 16.2% to 22.6%, against an average employment rate in the general population of 75%-80% (Haro, Novick et al. 2011). All these studies agreed that people with schizophrenia have lowest employment rate comparing to the general population as well as the 'disabled group'.

From a census done in Hospital Permai in 2014, a total of 583 referrals were received. Out of the total, 335 (57.5%) of them remained unemployed for reasons such as unable to work or securing a job and a minority of them refused to turn up for interviews or work. This study will focus on this small group of people which consist of 7.7% or 45 of the total referrals, according to the 2014 census. Among the unemployed group, there are distinct differences between those who refused to work and those who are not gainfully employed. This study aims at finding the reasons and associated factors why people with schizophrenia refused to work rather than factors remaining unemployed.

This survey seems to agree with other similar studies were done outside Malaysia which showed that majority of people with mental illness say they want to work (Hatfield et al 1992, Reker & Eikelmann 1997). It appeared that majority of people with mental illness seem to have difficulty in obtaining and sustaining a job, whereas only a minority of them refused to work or be employed for whatever the reasons. Reasons for job refusal will be the area of focus of this study.

2.2 Schizophrenia – The Course and Progress.

Morel from France in 1852 described a disorder that started in adolescence and leading first to withdrawal, odd mannerisms, and self-neglect, and eventually leading to intellectual deterioration. He later calls this disorder as 'demence precoce'. Emil Kraepelin in 1911 made the similar observation that a group of patients exhibiting psychotic symptoms are associated with rapid cognitive deterioration. He described this disorder as 'Dementia Praecox' also known as 'premature dementia'. This disorder was later coined by Eugen Bleuler as what we know today as 'Schizophrenia' simply meaning 'splitting of minds'.

Despite the fact that Schizophrenia had long been known to be associated with cognitive impairment, it was for many years a neglected component of schizophrenia, even though it is substantial and significant (Dickinson and Harvey 2009). Cognitive impairments are greater in early-onset schizophrenia (Rajji, Ismail et al. 2009). The impairments are seen across all domains of learning and memory, with the disproportionate involvement of semantic memory, working memory and attention. The deficits average 1 to 2 standard deviations below expected performance and are present even in the first episode. IQ is also noted to be reduced (Mesholam-Gately, Giuliano et al. 2009).

Cognitive aspects of schizophrenia are being actively researched due to several reasons. First of all, cognitive impairment of schizophrenia which some study said was evident

even during childhood before the onset of schizophrenia (Woodberry, Giuliano et al. 2008), is a major determinant functional outcome (Green 2006). The cognitive part of schizophrenia had also been postulated as the 'central of the disorder' and as underlying the psychotic symptoms (O'Connor, Harris et al. 2009). Lastly, it is now viewed as potential therapeutic targets. Meta-analysis provided good evidence for a beneficial effect of cognitive remediation therapy on cognitive outcomes, when combined with rehabilitation (Wykes, Huddy et al.) This in turn shown better outcome in schizophrenia.

It had been suggested that schizophrenia is a progressive and deteriorating illness (Curson, Barnes et al. 1985). And a long-term study by Bleuler in 1978, he proposed a step-wise deterioration in patients with multiple psychotic episodes (Bleuler 1978). The course of schizophrenia had been suggested that there are two phases — an active phase of deterioration starting in the prodromal phase and persisting through the early years after a first psychotic episode, followed by a chronic plateau phase which is a relatively stable phase (McGlashan 2006). It had been suggested that the first years of illness represent a "critical period" where the illness is at its most aggressive, the risk of relapse is high, and deterioration is most likely to occur (Birchwood, Todd et al. 1998). A study gave evidence that it is the relapse of the illnesses that caused the illness progression (Emsley, Chiliza et al. 2013). He concluded the importance of relapse prevention when managing people with schizophrenia. A study in 2012 by Zipursky et al suggested that the deterioration in cognitive function in schizophrenia, as evidenced by decrease in brain tissues volume, was due to other factors such as antipsychotic medications, substances abuse such as cannabis, smoking and alcohol, stress-related hypercortisolemia and low physical activities (Zipursky, Reilly et al.). He later suggested that mental health professionals need to join with patients and their families in understanding that schizophrenia is not a malignant disease that inevitably deteriorates over time but rather one from which most people can achieve a substantial degree of recovery. The cognitive

deficit has also been shown as an associated factor of unemployment among people with Schizophrenia (McGurk and Meltzer 2000). This was replicated by a local study in Malaysia (Midin, Razali et al. 2011) which also showed that there is an association between cognitive function and employment (attaining and maintaining). The authors further suggested integrating cognitive rehabilitation in the psychosocial rehabilitation program for patients with schizophrenia.

As we gain understanding about the course of Schizophrenia and how each relapses further damage the brain tissue, we also understood how motivation plays a significant and mediating role between neurocognition, social cognition, and functional outcome (Gard, Fisher et al. 2009). Hence, we started to realize the importance of managing people with schizophrenia as a whole. This brings us again back to the importance of 'functional recovery' in people with schizophrenia.

2.3 Functional Recovery

The majority of healthcare professionals still emphasize on treating the 'symptoms' and 'cure' as opposed to focusing on 'disabilities' and the social aspects of management (Boardman, Grove et al. 2013). Healthcare professionals seem to neglect the importance of work and employment and thus missed a huge part of the management of people with schizophrenia. As mentioned above, functional recovery encompassed: symptoms stability, independent living, work functioning, as well as social functioning (Kern, Glynn et al. 2009). As we start to appreciate the nature of Schizophrenia and its many bio-psycho-social managements, we also began to accept that full functional recovery is possible, even to the extent of full absence of all symptoms and disabilities and that optimal recovery should be a goal for people with schizophrenia (Harvey and Bellack 2009). It is worthwhile to note also that despite achieving functional remission, it does

not guarantee a successful functional recovery. Another author of a study (Dahlan, Midin et al. 2014) found, functional remission rate does not correlate with employment rate among people with schizophrenia. Recognizing these differences, healthcare professionals need to be educated on managing people with schizophrenia towards the goal of functional recovery rather than focusing on functional remission alone only.

2.4 Benefits of Employment

There are many ways of helping people with schizophrenia to return to function. Among them is to help them to gain employment. Being employed or merely being at work has a central role in most people's life, offering rewards beyond that of financial income. There are also benefits of non-financial income. Employment or work also not only benefit the individual themselves, but also the surrounding supporting groups and also makes a contribution to the country.

2.4.1 Financial Gain

The obvious benefit of employment is a financial or monetary gain to the individual. But besides benefiting the individual, another benefit of employment is to reduce the economic cost of unemployment and institutionalism. Boardman et al. found that 'the economic cost of unemployment among the mentally ill is high, both to the state and the individuals concerned (Boardman, Grove et al. 2003). A study by Wu et al estimated that the total cost associated with Schizophrenia stands at $62.7 billion in the USA in 2002. He concluded as well that the indirect excess annual costs associated with schizophrenia patients were estimated to be $32.4 billion (slightly more than 50% of total cost), with the largest component due to unemployment. The indirect costs are productivity loss: unemployment, reduced workplace productivity, premature mortality from suicide, and

family caregiving (Wu, Birnbaum et al. 2005). In summary, unemployment can be expensive and caused loss to the economy of the country, moreover so in people with schizophrenia where the loss of employment (loss of contribution to country's economy) is the highest compare to the general population in the productive age of 20-45 years old.

Another study in China (Phillips, Lu et al. 1997) reported an average total cost of admission is RMB691 with an average length of stay of 55 days. This further translates into a loss of productive days as well as economy loss. Therefore by helping patients to be successfully employed, patients' illnesses not only become more stable and thus reducing psychiatric admissions (Van Dongen 1996), they also become more financially independent. This will then reduce the economic cost of unemployment, institutionalism as well as psychiatric treatment and ward admissions.

2.4.2 Non-financial Gain

Undeniably, many studies showed that employment promotes recovery in people with schizophrenia (Bell, Lysaker et al. 1996, Mueser, Becker et al. 1997, Bond 2004, Dunn, Wewiorski et al. 2008). As a matter of fact, that is the goals of vocational rehabilitation, which are to help patients to achieve full-time competitive employment, acquisition of job-related skills, acquisition of any job (paid or volunteer), percentage of time in paid employment (full-time or part-time, competitive or sheltered), total job earnings, level of job (unskilled, skilled, etc.), job satisfaction, and job performance. It is also found that vocational rehabilitation may enhance outcomes other than work (non-vocational domains). These therapeutic outcomes include treatment compliance and symptom reduction, functional status in other areas (activities of daily living, maintenance of living situation, etc.), self-esteem, and subjective quality of life (Mueser, Becker et al. 1997). By gainfully employed, they will not only be gaining financial resources, but it will also

widen their social network which in turn improves their social functioning and becoming independent. A study by Shepherd showed that non-financial gains to the worker include social identity and status; social contacts and support; a means of structuring and occupying time; activity and involvement; and a sense of personal achievement (Shepherd 1989). All these gains also will aid in patient's self-esteem which eventually promotes recovery. The confidence and increased self-esteem from successful employment help to promote recovery in their illnesses. It had been shown that self-esteem plays an important role in the persistence of symptoms (Blascovich and Tomaka 1991).

Supporting the study by Blascovich and Tomaka, a study by Bell et al. also showed that getting a job in patients with schizophrenia has been shown to be associated with improvements in psychiatric symptomatology and lower hospitalization rates (Bell, Lysaker et al. 1996). A study (Provencher, Gregg et al. 2002) showed that many people with mental illness identify employment as crucial to their recovery process. All these points further highlighted the importance of 'returning to work' in patients with schizophrenia. With build-up interest in returning people with schizophrenia to the workforce by enabling them to work in competitive jobs (Becker and Drake 1993, Wehman, Revell et al. 2003, Marwaha and Johnson 2004), there is also an increase need for healthcare professional to understand the reasons for job refusal or barriers to unemployment for this group of people and tried to address their needs and difficulties that they may be facing.

2.4.3 Reduce Burden of Care

As we all know, schizophrenia is a severe and disabling chronic mental illness. It was estimated that 50% to 80% of persons with schizophrenia and related psychotic disorders

live with or have regular contact with a family caregiver (Gibbons, Horn et al. 1984, Lehman and Steinwachs 1998). These caregivers report high levels of burden related to caring for their family members (Grad and Sainsbury 1963, Gibbons, Horn et al. 1984). Besides putting a severe burden on the patients, caregivers experienced a significant 'Burden of Care'. In addition to the emotional, psychological, physical and economic impact, the concept of 'burden of care' often includes troubling feelings such as shame, embarrassment, feelings of guilt and self-blame. (Awad and Voruganti 2008). Hence, by helping a patient to be gain functionality and be more independent for themselves, this could lessen the burden of the caregivers, which in turn offer better support to aid patients' recoveries.

2.5 Barriers to Employment

A literature review revealed that unemployment is known to be harmful to the health of the general population (Bartley 1994, Bell, Lysaker et al. 1996). The importance of employment is once again highlighted in the literature review. Low employment rate or barriers to employment among people with schizophrenia has gained interest in many studies. This is in line with more studies showing the benefit of employments towards functional recovery. Barriers to employment can be classified as internal and external (Marwaha and Johnson 2004). Examples of external factors of unemployment are those related to the public as well as employer perception. Stigmatization of employers and public towards the people with schizophrenia may be an external barrier to employment particularly in less educated and psycho-educated about mental illnesses. A study showed that patients living in a small town anticipated stigmatization more often than those from the city although it was found that both actually experienced the same rate of stigmatization. (Angermeyer, Beck et al. 2004).

The internal barriers consist of people's attitudes and beliefs. A qualitative study design with two focus group revealed that these internal barriers consist of low self-esteem, a loss of motivation and acceptance of unemployment, worries and past experience (Bassett, Lloyd et al. 2001). Interestingly these attitudes are also found in the long-term unemployed in the general population (Blumenberg 2002). Another study also found that those who are unemployed are more fearful of working than those who are actually employed (Van Dongen 1996). The author found that a minority of participants said they were not well enough to work, although a greater number felt they were well enough to work on a part-time basis only. In addition, many subjects in research are worried that working might lead them to become unwell again, whereas some are concerned that working might affect the practicalities of taking medications as well as the side effects from the medications (Marwaha and Johnson 2004).

In summary, several studies showed reasons or associated factors for Job termination and low employment rate for people with severe mental illness, namely: Stigma (Manning and White 1995, Crisp, Gelder et al. 2000), self-esteem (Van Dongen 1996), negative symptoms (Van Dongen 1996), Psychosis (Van Dongen 1996), Side effects of Medications (Percudani, Barbui et al. 2004). Some patients are also concern over the loss of disability payments if they work is another factor or unemployment (Polak 1996, Rinaldi and Hill 2000).

2.5.1 Stigma and Self-esteem

Stigma is defined as 'a mark of disgrace associated with a particular circumstance, quality, or person' (Simpson and Weiner 1989). The stigma against people with mental illness is widespread and is seen across all culture and societies, both western and non-western (Crisp, Gelder et al. 2000, Gray 2002, Adewuya and Oguntade 2007, Thornicroft,

Brohan et al. 2009). The stigma is often felt not only by the patients but also their support groups namely their family and relatives (GonzÃ¡lez-Torres, Oraa et al. 2007). There are two aspects of stigmatization: (1) Patients' perceptions of stigmatization and (2) the actual stigmatization experiences. The first one, the patients' perception of stigmatization is also known as self-stigma or anticipated discrimination. For a person to have 'self-stigma', he/she must first be aware of the stereotype that describes the stigmatized group, agree with it and then apply it to the self (Corrigan, Larson et al. 2009). It is postulated that when a patient agrees with the negative stereotypes associated with, for example, Schizophrenia, he/she will turn these stereotypes inwards against himself/herself, resulting in reduced self-esteem. This process is referred to as 'internalizing stigma' (Watson, Corrigan et al. 2007). A study also revealed that 'internalizing stigma' or 'self-stigma' can also occur after exposure to discrimination from the public (Fung, Tsang et al. 2008). Stigma is known to interfere with treatment and recovery of people with mental illness particularly schizophrenia. High self-stigma has been related to poor adherence with psychosocial treatment (Fung, Tsang et al. 2007, Fung, Tsang et al. 2008) and pharmacological treatment (Sirey, Bruce et al. 2001, Adewuya, Owoeye et al. 2009). This will later impede the recovery of the illness.

Self-stigma has also been shown to associated with unemployment by many studies (Manning and White 1995, Marwaha and Johnson 2004). It is often because of this self-stigma, patients are not keen to reveal their mental illness to their employers for fear of being rejected and stigmatized. A sizeable proportion of the general public interviewed in a survey believed people with schizophrenia were dangerous and difficult to talk to (Crisp, Gelder et al. 2000). Stigma and discrimination from employers (Manning and White 1995) may be a potent barrier to employment. Most participants talked about enacted stigma (a mark of disgrace or discredit that marks a person out from others) as an important determinant of their chances in the job market at some point during the

interviews and there is substantial evidence for this from previous studies (Manning and White 1995, Crisp, Gelder et al. 2000). Conversely, employment has also been shown to help reduced self-stigma experienced by the patients (Perkins, Raines et al. 2009). However, the exact association between self-stigma or anticipated discrimination and employment are not exactly known. We are not sure if the stigma anticipated by the people with schizophrenia is different between the employed and unemployed. This study will also attempt to explore it.

This self-stigma is closely associated with self-esteem and self-efficacy of sufferers of mental illness. The stigma associated with mental illness harms the self-esteem of many people who have serious mental illnesses (Link, Struening et al.). Experiences by mental illness sufferers had unfortunately led to stigmatization followed by lowered self-esteem. A study directly compares the stigmatization and lowered self-esteem. It showed that stigma led to self-deprecation, which in turn compromised feelings of mastery over life circumstances (Wright, Gronfein et al. 2000). This further brings us to the effect of lowered self-esteem among people with schizophrenia and employment. Many studies found an association between unemployment and low self-esteem (Link, Struening et al. , Van Dongen 1996, Marwaha and Johnson 2004). However, most are inconclusive whether it is the employment that helps increase the self-esteem or vice versa. Again, this study will try to compare the self-esteem between two groups of patients namely the group refusing to work and the group agreeing to work.

2.5.2 Symptoms of Schizophrenia

Schizophrenia is a severe and chronic disabling mental disorder. It is often characterized by delusions and hallucinations. To be diagnosed to have schizophrenia, one has to be presented with two or more of the following symptoms for a period of more than a month:

(1) Delusions; (2) Hallucinations; (3) Disorganized speech (eg, frequent derailment or incoherence) (4) Grossly disorganized or catatonic behavior; (5) Negative symptoms (ie, diminished emotional expression or avolition) (DSM-V, APA). Another criterion was the presence of dysfunction either in work or social and more often than not both. Indeed, some researchers agreed that this dysfunction of decreased level of functioning is the main core symptoms of schizophrenia illness.

Schizophrenia is often termed as positive and negative symptoms. Crudely, the positive symptoms are the presence of feelings or beliefs that are usually not present for instance hallucinations and delusions; whereas negative symptoms are associated with lack of feelings or beliefs such as loss of motivations and emotions. Both of these symptoms can be presented as a barrier to employment for people with schizophrenia (Van Dongen 1996, Marwaha and Johnson 2004). However, when there were obvious positive symptoms, especially when there was an acute phase or episode of schizophrenia, it was relatively easier to comprehend how it affected people with schizophrenia to work. 'Acute phase' is sometimes defined as 'psychosis episode with a predominance of positive symptoms' (Mathews, Tesar et al. 2013). But when the person with schizophrenia has deemed recovered from that acute phase, recovering from 'chronic phase', it was difficult to understand why they remained at the low level of functioning. Some researchers describe this phase as a chronic phase as 'phase with a predominance of negative symptoms and cognitive deficits'(Mathews, Tesar et al. 2013). Most studies done had shown evidence that negative symptoms are linked with poorer social functioning (Sayers, Curran et al. 1996, Konstantakopoulos, Ploumpidis et al. 2011, Rocca, Montemagni et al. 2014). And negative symptoms have appeared to be key predictors of functional outcome in people with schizophrenia (Green 1996, Fervaha, Foussias et al. 2014, Galderisi, Rossi et al. 2014, Rocca, Montemagni et al. 2014). Although a local study had been done and had found an association between negative symptoms of

schizophrenia and unemployment (Midin, Razali et al. 2011), their study was comparing employed and an unemployed group of people with schizophrenia. This study, however, will focus on the association between negative symptoms and the group refusing to work. As per definition, there is a slight distinction between people who are unemployed and refused to work, so this study will attempt to explore this area. In addition to this, previous number of jobs which will be explored in this study, as it reflects the motivation for people with schizophrenia to work and also in some ways the premorbid functioning before the onset of the disease.

2.5.3 Medications

Since the discovery of Chlorpromazine as antipsychotic by chance in the 1950s, medication or pharmacological treatments had become the mainstay of treatment for people with schizophrenia. To date, there are two groups of antipsychotics specifically the first generation and the second generation antipsychotics. Both groups of antipsychotics are reported to be effective in reducing the positive symptoms of schizophrenia mentioned above though it was reported in some studies that the second-generation antipsychotics are more effective in reducing the negative symptoms (Arndt, Andreasen et al. 1995). However, another study showed that even newer second-generation antipsychotics also does not help in returning patient with schizophrenia to pre-morbid function level (Meltzer and McGurk 1999). To promote better response, adherence and tolerability there are also antipsychotics which come in the form of depot injections. This reduces the need for patients to take medication daily but at longer intervals such as weekly to monthly.

The first generation antipsychotics also known as typical antipsychotics are usually associated with more unwanted side effects, such as the Extrapyramidal Side effects

(EPS); whereas the second-generation antipsychotics are associated with metabolic side-effects such as weight gain and diabetes (Garver 2000, Green, Patel et al. 2000). EPS or neuroleptic-induced movement disorders can take a number of forms. The most common of these is akathisia, an inner sense of restlessness that may be accompanied by overt restlessness and fidgeting. The other common form is dystonia, which is characterized by an involuntary muscle spasm of large muscles, usually neck (torticollis), limbs, and trunk. And lastly, there is Parkinsonism, which usually comprises bilateral tremor of the extremities, rigidity, gait instability with shuffling, and bradykinesia. EPS can be incapacitating, are often troublesome to not only the patients and their families. EPS can also be anxiety-provoking and at times more than the original psychotic symptoms themselves. These side effects are thought to be due to the blockade of the dopamine D2 receptors in the nigrostriatal tract (Glazer 1999). Nevertheless, EPS are still associated with second generation or atypical antipsychotic use albeit at a lesser rate (Beasley, Tollefson et al. 1996, Arvanitis and Miller 1997). Other common side effects associated with antipsychotics use include daytime drowsiness, somnolence, hyperprolactinemia, sexual dysfunction and Gastrointestinal upset (Beasley, Tollefson et al. 1996, Kleinberg, Davis et al. 1999). These side effects can be very disabling and difficult to cope with.

Though there had been a considerable advancement in psycho-pharmacotherapy, people on antipsychotic still inevitably suffer from their side effects. Some of which are difficult to distinguish from the negative symptoms of schizophrenia (Rifkin, Quitkin et al. 1975, Lewander 1994). The ‘motor side effects’ as well as ‘non-motor side effects’ from antipsychotics can mimic negative symptoms, namely indifference, apathy, and avolition (Artaloytia, Arango et al. 2006).

In summary, clinicians not only need to be well-versed with medication side effects but should always be trying to find the right balance between the side effects and the symptoms they are having. There had been studies associating these side effects with

unemployment (Marwaha and Johnson 2004, Percudani, Barbui et al. 2004). This study will attempt to find out if the refusal to work is associated with medications side effects.

2.5.4 Substance use disorder

Substance disorder had long been associated with low rate of unemployment. This was confirmed by as systemic review which reviewed publications between 1990 till 2010. The study further showed that not only substance misuser had difficulty searching and securing a job, but they have higher chances of relapse (Henkel 2010). However, the exact association between substance and unemployment are more complicated.

To make matter more complicated, there are high comorbidity between substance usage and people with schizophrenia. Some study quoted as high as 50% of people with schizophrenia use alcohol and illicit drugs. The study also showed that 70% of them are nicotine-dependent (Brady and Sinha 2005).

2.5.5 Demographic factors

Demographic factors such as age and gender had not been found to be associated with being employed. This had been confirmed by both western study done in Poland (Kiejna, Piotrowski et al. 2015) as well as another study in India (Srinivasan and Thara 1997). However one of the confounder in the studies is the comorbid medical illness associated with age. Having said that, this study will exclude those who are medically ill and unfit to work as well as those over age 60 years old.

The former study by Kiejna in 2015, also found that lower education was associated with worse vocational outcome. This could be related to lower pre-morbid functioning and the earlier age of onset of illness, which denied patient from furthering higher education.

Having said this, the study was looking at 'ability' of people with schizophrenia to work, whereas this study will explore why people with schizophrenia refused to work.

There is evidence that found strong association between good pre-morbid functioning and favourable outcome in people with Schizophrenia (CARPENTER JR and Strauss 1991). Good premorbid functioning could also be translated into length of job duration held before onset of illness. This will be one of the employment characteristic that this study will be looking into. In addition to this, previous number of jobs will also be explored in this study, as it reflects the motivation for people with schizophrenia to work and also in some ways the premorbid functioning before the onset of the disease.

None the less, in another study done in Turkey (Alpa, Sefilb et al. 2015), who looked into education level and employment in general non-clinical population, it was found that those with higher education had more difficulties in finding a job compared to those with lower education. This is due to relatively more blue-collar jobs available, compared to white-collar job. Of course, the result from above study had to be looked into with caution as it does not project the population of this study. However, interestingly, the IPS Supported Employment program in Hospital Permai also faced similar difficulty in searching white-collar jobs for clients interested in returning to work. Perhaps this is one of the areas that future study should look into.

2.5.6 Duration of unemployment

Parson's sick role states that when one falls sick, they are obliged to try to get well (Parsons 1975). Unfortunately, in mental health, the duration of illness is often long. According to study in the United Kingdom, the average leave of absence due to mental health is 21 days (Spurgeon 2007). This may be translated into duration of unemployment. It is further found that the longer a person is off sick, the more difficult it becomes for

them to return to work and the less likely it is that they will return to work at all (Henderson, Glozier et al. 2005). When a person with mental illness suffered from a relapse, the episodes are often traumatizing as well as dehumanizing especially when it deals with involuntary admission. This is made worse if they associated employment with the symptoms they are suffering and hence further delay or rejection to return to work (Jones, Huxtable et al. 2005). This study shall attempt to find association between job refusal and duration of unemployment.

2.5.7 Cognition

As discussed earlier, people with schizophrenia are often suffering from cognitive deficit which usually affect all domains of learning and memory impairing attention, working memory, verbal learning and memory, and executive functions. For some time, clinicians thought that poor cognitive function are associated with poor vocational outcome. While study had shown that cognitive impairment in severe mental illness are predictors of poor outcome in schizophrenia (Green 1996, Green, Kern et al. 2000), but more recent study had shown weak association between cognitive impairment and employment status of people with schizophrenia. For instance, a study (Bowie, Reichenberg et al. 2006) found that cognition is not a direct predictor of outcomes. The study concluded that negative symptoms and depression are associated with real world performance independent of cognitive performance. Another study done in India (Srinivasan and Tirupati 2005) also found that there is no association between employment and cognitive status in people with schizophrenia.

CHAPTER 3

RATIONALE OF STUDY AND OBJECTIVES

Most of the studies done observed the reasons or associated factors for unemployment among people with mental illness. As per definition, there are subtle differences between 'unemployed' and 'refusal to be employed'. As mentioned in the literature review, there are two types of barriers to employment, namely 'internal' and 'external' barrier. A patient might refuse the job offered to him/her or he/she might have difficulty in finding a job for himself/herself. This study will focus on exploring the internal barriers that might be faced by the people with schizophrenia. This is in contrast to some studies where the study subjects consist of a mixture of mental illness, for instance, schizophrenia, and bipolar disorder. Studies have shown that the unemployment rate is different, between schizophrenia and bipolar disorder, where notably, the employment rate is higher in people with bipolar disorder (40%-60%) than people with schizophrenia (16.2%-22.6%) (Haro, Novick et al. 2011, Marwaha, Durrani et al. 2013, Taskila, Steadman et al. 2014). This could mean that the barriers that are faced by two distinct groups of mental illnesses are different in some way.

To date, no local research had been done to explore why people with schizophrenia refused to work. A local study (Midin, Razali et al. 2011) which found an association between unemployment among people with severe mental illness and cognitive deficits. Another local study (Kasim, Midin et al. 2014) also found that good past working history and getting a preferred job were significant predictors of successful employment. The author of another local study (Dahlan, Midin et al. 2014) found that despite having a high rate of functional remission among people with schizophrenia, this group of people

remains to have low employment rate. Hence, understanding the complexity of human behavior and schizophrenia this study will employ a mixed-method design in attempting to look into other possible reasons for job refusal among people with schizophrenia.

Besides, Malaysia being unique to itself and the notable differences in the welfare system, family supports and dynamics, diversity in race, religion and culture as well as economic needs and structure might have different findings than studies which had already done outside Malaysia.

3.1 Research Questions

1. What are the reasons for Job Refusal among people with Schizophrenia in Hospital Permai, JB?
2. Are the factors limited to Stigma, Self Esteem, Negative/Positive symptoms and Side effects of medications as showed by other previous research or are there more?
3. Are there any other reasons why the majority of the patients with Schizophrenia refused to work?

3.2 General Objectives

To explore and clarify the reasons for Job refusal among people with schizophrenia referred to Occupational Therapist for Supported Employment in Hospital Permai, Johor Bahru.

3.3 Specific Objectives

1. To determine the association between Jobs Refusal among people with schizophrenia with Patients' own perceived stigma.
2. To explore whether the reason for Job Refusal among people with schizophrenia is associated with their schizophrenia symptoms.
3. To determine if there is any association between Job refusal and patients' self-esteem.
4. To determine if there is an association between medications' side effects and Job refusal.
5. To determine if there is association between job refusal and duration of unemployment.
6. To determine if there is association between job refusal and number of previous jobs.
7. To determine if there is association between job refusal and longest job held.
8. To determine if there is association between job refusal and socio-demographic.
9. To explain any significant or insignificant findings from quantitative part of this study.
10. To gain views from the participants' perceptive (people with schizophrenia) regarding reasons for job refusal.

3.4 Research Hypothesis

There are no associations between refusing to work and stigma, self-esteem, negative symptoms, positive symptoms of patients with schizophrenia referred for Supported Employment in Hospital Permai, Johor Bahru.

CHAPTER 4

METHODOLOGY

4.1 Study Setting

Hospital Permai was built in 1937 and is at present, the second largest mental institution in Malaysia. It provides a variety of psychiatric services e.g. in-patient and out-patient services for general psychiatry, child and adolescent psychiatry, community psychiatry, addiction psychiatry and forensic psychiatry. It is also a secondary and tertiary referral center for the southern and eastern states of Malaysia i.e. Negeri Sembilan, Melaka, Johor, Kelantan, Terengganu, and Pahang.

The Supported Employment Program was set up in Hospital Permai in July 2009. It is managed by a team of occupational therapists. To date, there are eighteen Employment Specialists overseeing the clients enrolled in the supported employment program. Job placement referrals are mainly from within Hospital Permai itself but the team also accept referrals from nearby health care centers such as Hospital Sultanah Aminah Johor Bahru, Hospital Sultan Ismail Johor Bahru, Hospital Kulai, Hospital Kota Tinggi, Hospital Pontian as well as Klinik Kesihatan Pekan Nenas and Klinik Kesihatan Masai.

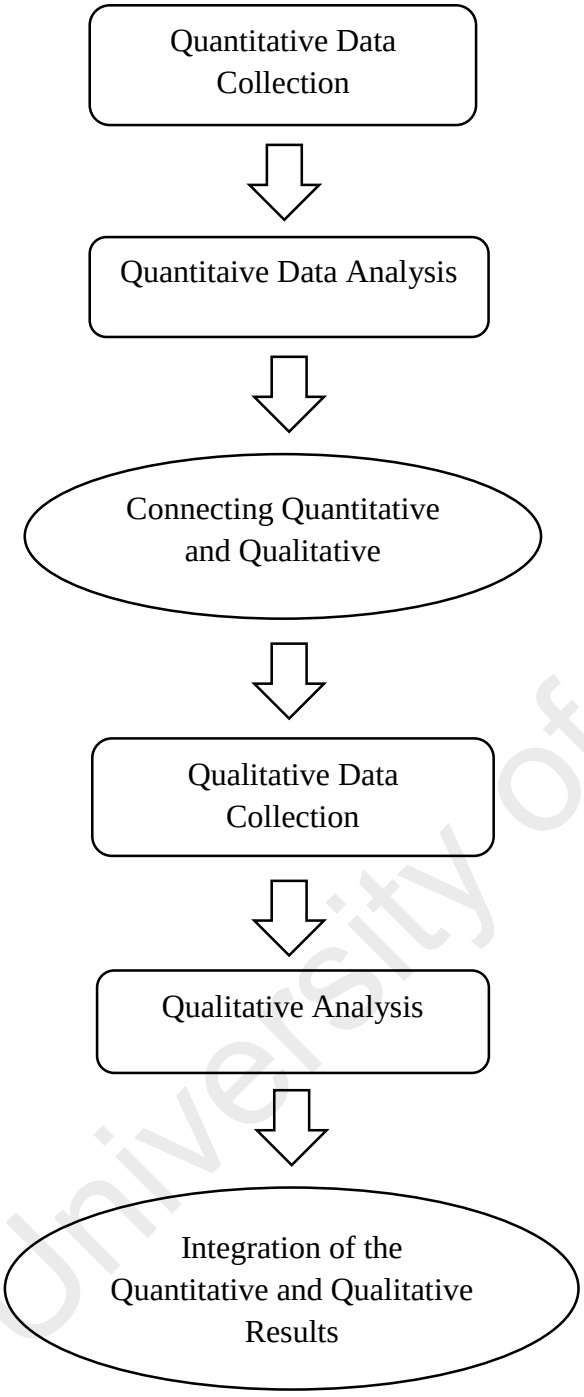
4.2 Study Design

This study utilized Mixed Method, Sequential Explanatory Design (Creswell and Clark 2007). This study will address why people with Schizophrenia refused to work. An explanatory mixed methods design will be used, and it will involve collecting qualitative data after a quantitative Part in order to explain or follow up on the quantitative data in more detail.

Part 1 study employed explorative, observational, cross-sectional study design. In the first quantitative Part of the study social-demographic data, employment data and clinical data will be collected from participants of the study to test if there are any differences in term of employment characteristics as well as clinical characteristics (anticipated discrimination, self-esteem, side effects of medications experienced and symptoms of schizophrenia) between two group of participants (agreed to work and refused to work).

The second qualitative Part will be conducted because we believed that there is a gap in understanding why people with schizophrenia refused to work rather than a failure to be employed per se. The previous study had attempted to study the barrier to unemployment that these people faced. In this exploratory follow-up, the reasons for job refusal among people with schizophrenia will be tentatively explored in Hospital Permai. The reason for the exploratory follow-up is to help explain the quantitative results be it significant (or non-significant), outlier or surprising results that we gathered via the first part of this study (Creswell and Plano Clark, 2007: 71–2). The flow chart below summarized the Mixed Method Sequential Explanatory Design used in this study (Figure 4.1):

Figure 4.1 Mixed Method Sequential Explanatory Design



4.3 Period of Study

This is an Explanatory Sequential Mixed Method Study. Hence, the study was done in two parts, namely the Part 1 and Part 2. The part 1 of the study applied explorative, observational, cross-sectional study method and analyzed the data gathered quantitatively. The part 1 of the study will be done from 1st January 2015 to 31st May 2015. Part 1 of study includes 3 months of data collection plus 3 months of data analysis as well as planning for part 2 of study.

The second part of the study focused on qualitative data collection and analysis. This involves selection of participants for individual interviews and focus group interviews. Part 2 of the study are to be done from 1st June 2015 till 31st August 2015.

4.4 Study Population

The source population for this study is the patients who are referred to Employment Specialists in Hospital Permai, Johor Bahru for Job search and placement, under our Individual Placement and Support (IPS) or Supported Employment program.

4.5 Inclusion Criteria

1. Patients diagnosed with schizophrenia according to DSM V criteria.
2. Patients between 18 to 60 years of age.
3. Patients who are able to give consent.

4.6 Exclusion Criteria

1. Patients who are diagnosed with mental retardation.
2. Patients who are unable to give consent.

4.7 Part 1 of Study - Quantitative

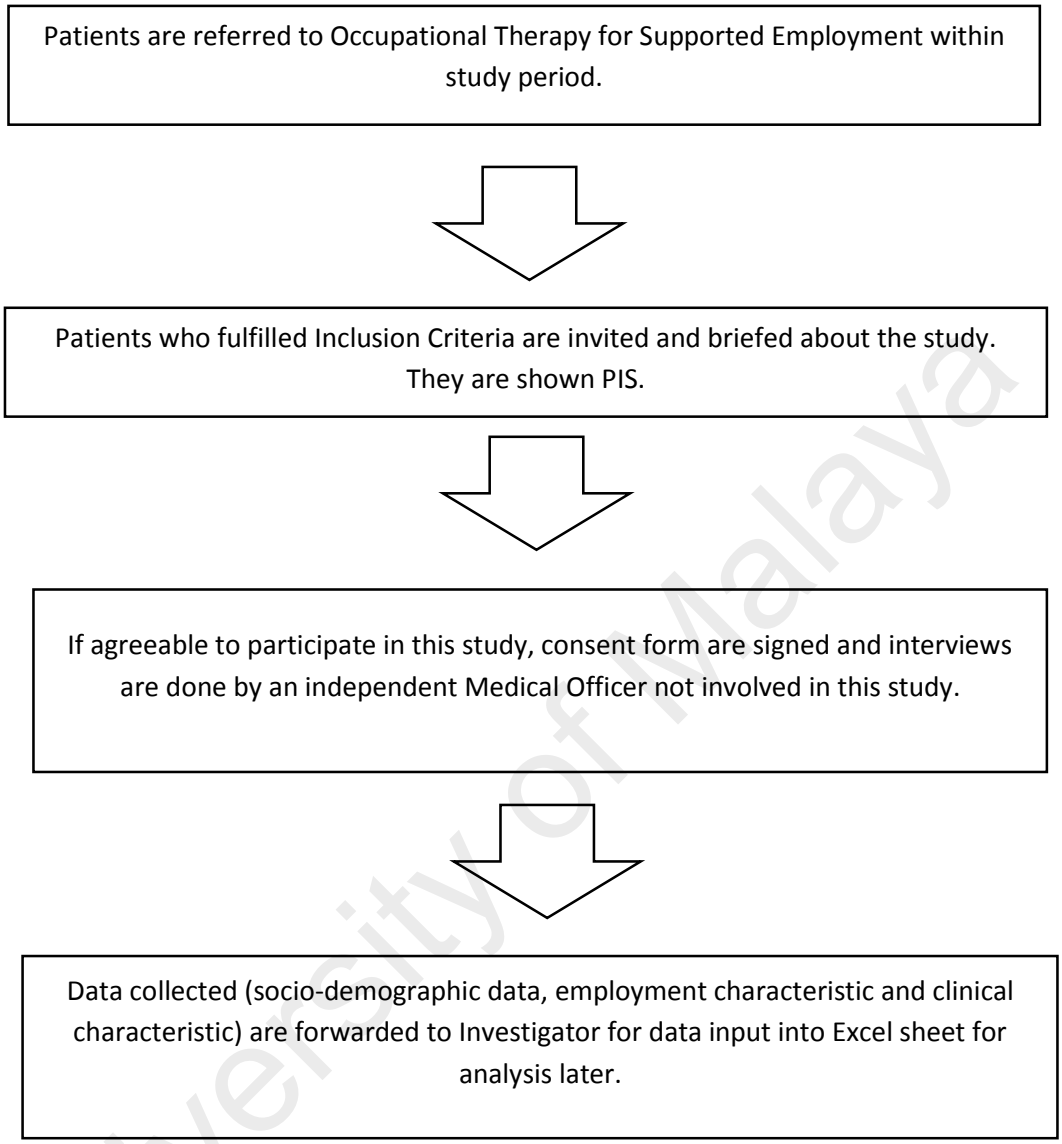
4.7.1 Data Collection

As this is census sampling, all referrals between January 2015 and March 2015 will be invited to join in this study. Employment Specialists are briefed on the study to be done, specifically on the inclusion and exclusion criteria of this study. Referrals that are received are registered at Occupational Therapy Complex, Hospital Permai, Johor Bahru. Subsequently, respective Employment Specialists will be contacted depending on the source of referrals. If the patient was around at registration, they would be screened and if fulfill the inclusion criteria, they would be invited to participate in this study. If the patient was not around at registration, they would be contacted and briefed about this study. If agreeable to participating, the appointment was made to meet them at Occupational Therapy Complex, Hospital Permai, Johor Bahru.

Those patients who agreed to participate, they will be shown Patient Information Sheet. They will be informed that the participation is voluntary and they may withdraw at any time. They are reassured of their confidentiality and be told that the information they provided would only be used for research purposes. The result of the data obtained will be reported in a collective manner with no reference to a specific individual.

After signing the consent form, patients would be interviewed and assessed using the questionnaires and instruments prepared. The interview and assessment would be done by a designated Medical Officer in charge of Occupational Therapy, who was not involved in this study. The whole interview (including 3 self-rated questionnaires as well as 1 clinician-rated PANSS) would take around 60-75 minutes. Those who decided to not participate in the study are thanked for their time. Flow Chart below summarized the sequence of Sample Collection (Figure 4.2):

Figure 4.2 Sequence of Sample Collection



4.7.2 Sample Size Calculation

Sample size calculation for this study takes into consideration that there is limited resources in term of investigators, time and budget allocated for this study. Nonetheless, the sample size of this study was calculated using the formula by Metcalfe (Metcalfe 2001):

$$n = \frac{Z^2 P(1-P)}{d^2}$$

Where,

n = sample size

Z = Z statistic for a level of confidence,

P = expected prevalence or proportion

d = precision

In this study, Z was set at 1.96 which correspond to the level of confidence of 95%.

Unfortunately, there are no study done locally that look into prevalence of 'people with schizophrenia who refused to work'. Of note, this is not the same as prevalence of people with schizophrenia who are not employed. Malaysia' National Mental Health Registry recorded unemployment rate among people with schizophrenia to be as high as 70%. But this proportion included those who are 'not able' to work as well as those who 'refused' to work. In contrary, Hospital Permai's Occupational Therapy Unit's statistic in 2014 registered 45 or 7.7% that 'rejected and refused to work' after being referred for Supported Employment. Hence, in this study, taking into account of the uncertainty of the prevalence of people with schizophrenia who refused to work, we decided to select the proportion (P) of 50% which would lead to larger sample size.

Due to resource limitation, (budget and time as well also being exploratory preliminary study where no study had done before locally and perhaps internationally, that looked into this specific population) a larger d was used, 10% (d=0.1) (Naing, Winn et al. 2006).

Thus from the calculation, the recommended minimum sample size is 96. Within the duration of this study, a total of 96 patients were successfully invited to participate in this study.

4.7.3 Instruments

a. Social Demographics, Clinical history and work characteristics. – Appendix B

This is a self-generated questionnaire which will be used to record patient's demographic data, other related information e.g. clinical history, work characteristics. The psychiatric diagnosis will be obtained from the patient's clinical case record.

b. Positive and Negative Symptoms Scale (PANSS) – Appendix C

The Positive and Negative Syndrome Scale (PANSS) was published in 1987 by Stanley Kay, Lewis Opler and Abraham Fiszbein. It is a clinician-rated scale and usually required 45 to 60 minutes to administer. The interviewer will be trained to a standardized level of reliability.

The PANSS is consist of three scales namely Positive, Negative and General Psychopathology Scale (Kay, Flszbein et al. 1987). Both the Positive and Negative scale consist of 7 items, whereas the General Psychopathology scale consists of 16 items. The minimum score of PANSS is 30 and the maximum is 210.

In this study, the interviewer will be trained beforehand by a qualified instructor. This will ensure the reliability of the scale. A designated Medical Officer, who is trained to use PANSS, will be assigned to conduct the PANSS. He or she will not be involved in this study, this is to prevent bias in the rating.

c. Questionnaire on Anticipated Discrimination (QUAD) – Appendix D

This is a patient self-rated questionnaire and developed by Gabbidon J et al. and published in 2013. It has 14 items and had been tested to show good reliability and validity. Each item can be scored from 0 (strongly disagree) to 3 (strongly agree) with higher scores

indicating greater anticipated discrimination. QUAD had been used and validated among people with mental illness by the author. The 14 items in QUAD had good internal consistency (alpha = 0.86), good test re-test reliability (ρ(c) = 0.81) and adequate convergent validity: correlations with the Internalized Stigma of Mental Illness (ISMI) scale ($r = 0.45$, $p < 0.001$) and with the Stigma Scale (SS) ($r = 0.39$, $p < 0.001$) (Gabbidon, Brohan et al. 2013).

This questionnaire has been chosen for this study because it is self-rated. This allowed patients to be able to answer the questionnaire by themselves and is, therefore, more appropriate to measure anticipated stigma that may or may not be present in patient's life.

Due to the diversity of culture in Malaysia, this scale will also be translated into Malay and Chinese. Permission to use this questionnaire has been obtained from the developer.

Unfortunately due to time constraints, only stage 1 and 2 of the translation are done. The original QUAD in English would be translated into Malay and Chinese by two different individuals who are fluent in three languages. These are then back-translated to identify any issues of translation. After that, at stage 2, translated version of QUAD (Malay and Chinese) will be administered to Job Placement officers and Medical officers in Hospital Permai, Johor Bahru as a pilot test. Any further words or language flaws will be further identified and corrected.

d. Rosenberg Self-Esteem Scale (RSES) – Appendix E

The Rosenberg Self-Esteem Scale (RSES) is a self-rated questionnaire widely used to measure self-esteem. It is developed by the late Dr. Rosenberg who was a professor of sociology at the University of Maryland in the 1960s. While designed as a Guttman scale, the RSES is now commonly scored as a Likert scale. The 10 items are answered on a 4-point scale ranging from "strongly agree" to "strongly disagree". The scale ranges from

0-30, with 30 indicating the highest score possible. The scale generally has high reliability, with test-retest correlations value between 0.82 and 0.88. The Cronbach's alpha of the scale in the present study was 0.67. Other scoring options are possible. There are no discreet cut-off points to delineate high and low self-esteem.

The RSES has been tested for high reliability. For practical purposes in the local setting, all three languages of RSES will be used, English, Malay, and Chinese. Both the Malay (Jamil 2006) and Chinese (Yeung and 楊家正 1998) RSES has been translated. The author of the translated RSES had been contacted and given permission to use the translated version of RSES.

e. Glasgow Anti-psychotics Side-effect Scale (GASS)- Appendix F

Glasgow Antipsychotic Side-effect Scale (GASS) was developed in 2007. It was validated against Liverpool University Neuroleptic Side Effect Rating Scale (LUNSERS) (Waddell and Taylor 2008). GASS is a self-rated questionnaire consisting 22 items with each item scoring between 0 to 3, with 0 being the lowest and the highest score being 66. A score of 0-21 indicates absent or mild side effects. Whereas the score of 22-42 indicates moderate side effects and finally score of more than 43 indicates severe side effects.

It covered several side effects namely, CNS effects, Cardiovascular effects, Extra-pyramidal effects, anticholinergic effects, Gastrointestinal effects, Genitourinary effects, screening for diabetes mellitus, prolactinaemia effects, and weight gain.

Due to the diversity culture in Malaysia, the questionnaire will be into Malay as well as the Chinese language. Unfortunately due to time constraints, only stage 1 and 2 of the translation are done. The original GASS in English would be translated into Malay and Chinese by two different individuals who are fluent in three languages. These are then

back-translated to identify any issues of translation. After that, at stage 2, translated version of GASS (Malay and Chinese) will be administered to Job Placement officers and Medical officers in Hospital Permai, Johor Bahru as a pilot test. Any further words or language flaws are further identified and corrected.

4.7.4 Statistical Analysis

The data in this study was analyzed using the Statistical Package for Social Sciences (SPSS) version 17.

For demographic data, variables such as gender, ethnicity, religion, marital status, education level, employment status, history of ECT and medications group were expressed as categorical data.

Age, number of previous jobs, longest job, duration of unemployment, duration of illness, number of previous admissions, Rosenberg Self-esteem scale (RSES), Questionnaires on anticipated discrimination (QUAD), Glasgow Antipsychotics Side effect Scale (GASS) and Positive and Negative Symptoms Scale (PANSS) were expressed as continuous data.

Normality testing was performed first. From Kolmogorov-Smirnov test, it was found that the data distribution was not normal. Therefore, further data analysis was performed using non-parametric tests.

As there were two groups of subjects namely those agreed to work and those refused to work, bivariate analysis was carried out. Chi-square test was used to compare the relationship between categorical variables and both groups. Since the data is not normally distributed (one arm is less than 30), Mann-Whitney U test was performed to compare relationship of continuous variables and both groups.

Subsequently, factors found to be significant at bivariate analysis ($p<0.05$ was chosen as significance level in this study) were identified and multiple stepwise logistic regression was used to identify factors associated with job refusal among people with schizophrenia in Hospital Permai.

4.8 Part 2 of the Study - Qualitative

4.8.1 Sampling Frame

In qualitative studies, the aim is not to be representative of the population. The validity, meaningfulness, and insights generated from such studies have more to do with the information richness of the cases selected, and the analytical qualities of the researcher than with the sample size. There are no rules for sample size in qualitative research. It depends on what one wants to know, the purpose of the study and practical factors.

Hence for the qualitative arm of this study, purposeful sampling method shall be used. Purposeful sampling means that researchers intentionally select participants who have experience with the central phenomenon or the key concept being explored (Hanson, Creswell et al. 2005).

Participants from Part 1 of the study that refused to work are identified. 19 patients are identified in total. They are selected based on their contactable as well as ability to be interviewed (spontaneous speech, good rapport, minimal symptoms of schizophrenia as well as good concentration). They are then contacted by phone and are told about the reasons for contacting them, i.e. for individual interviews. Their family members are invited for the interview as well, because we felt that family played an important role in recovery of the patients.

However, only 8 of them and a family member agreed to participate. 2 are unreachable by phone and 4 of them quote distance of travel as a reason for not participating. 3 gave reasons for not having transport. Another 2 agreed to come for an interview but eventually did not turn up.

The 8 plus a family member who agreed to come for interview are given appointment according to their free time. The interviews are held at Occupational Therapy Complex, Hospital Permai. The individual interviews lasted from 30 minutes to 45 minutes.

13 Employment Specialists are also selected for Part 2 of study to participate in Focus Group interviews. They are divided into two groups. Group dividing is based on a mixture of duration (months) of experience in running Supported Employment Program as well as the area of coverage (Urban vs Rural). The Focus Group Interviews lasted around 45-60 minutes.

4.8.2 The Interviews and Settings

a. Individual Interviews

The interviews were conducted in three languages; Malay, Chinese, and English. A semi-structured interview questions (Appendix G) was developed after analyzing the results of Part 1 of this study. The interview questions were used to explore the reasons for job refusal among people with schizophrenia in Hospital Permai as well as trying to explain the results from Part 1 of study. Having said so, the questions prepared merely act as a guide and the participants of the interviews still eventually determined the content and flow of the interview (design flexibility). This is to allow them to introduce new relevant themes that might arise. Even though our primary interest is exploring the views and experiences related to job refusal, but the scope of the discussion also include the difficulties or other barriers that the participants might face in the search of employment.

The individual interviews were conducted by the principal investigator in three languages according to the preference of the participants. The interviews took in between 30 minutes to 45 minutes and are recorded using a digital recorder. To familiarize with the data, the same principal investigator transcribed the recordings into Microsoft Word in the original language. The transcripts would then be compared once more with the recordings to ensure accuracy.

The participants that refused to work from the part 1 of the study are contacted via phone and invited to attend the individual interview. When agreed, appointments are given within office hours (Sunday to Thursday, 8am till 12pm). The interviews are spaced out with maximum 2 interviews per week to allow time for transcribing the recordings and identification of themes. This is to allow 'constant comparison' to check for 'saturation'. Courtesy call a day before the appointment was made to remind them of the individual interviews.

The venue of the interview is done at 'assessment room' inside Occupational Therapy Complex in Hospital Permai. The setting of the room is similar to those in outpatient clinic. Privacy and confidentially can be assured when the interview is in the progress.

The participants were once again explained the detail of this research and informed consent was obtained from the participants before starting the interviews which lasted from 30 minutes to 45 minutes.

b. Focus Group Interviews and Settings

13 Employment Specialists of similar seniority (this is to encourage dynamic interaction) were invited to join the Focus Group Interview (FGI), they were then divided into two groups for FGI. The reason for FGI is to take the advantage of the interaction between group members which would allow more information and richer data to be collected (Krueger and Casey 2009). An interview guide (Appendix H) was developed after analyzing results from Part 1 of study as well as the individual interviews; this will act as a guide for the FGI session. The primary objective is to explore the reason why patients under their care refused to work. The discussion will also be extended to the difficulties that their patient faced during job searching.

Before the start of FGI, basic relevant demographic details including age, gender, and duration of service as Employment Specialists were collected. The FGIs were conducted in Malay Language (preference by majority) and were led by the principal investigator. The FGIs were recorded on a digital recorder and was later transcribed by the principal investigator, to allow data familiarization, into Microsoft Words in the Malay Language. FGIs lasted around 45 minutes to 60 minutes.

The group interviews are to be carried out in meeting room with seats and round table. The meeting room is situated inside the Occupational Therapy Complex in Hospital Permai. The participants of the interviews are explained in detail regarding the study and informed consent was obtained from them before the start of the interview.

4.8.3 Analysis

Below summarized the steps of thematic analysis that were taken using the 'Deductive Research Approach' or 'Theory-Driven Approach' (Hayes 1997, Boyatzis 1998):-

1. Data familiarization. – This is the stage where the principal investigator does the transcription and later does the checking of the transcript and finally reread the transcripts a number of times to familiarized with the data.
2. Themes creations – Themes are created from literature review as well as from the results of Part 1 of the study. This allows the investigator to look for similar themes later.
3. Breaking up the Transcripts – The transcripts were broken up and relocated into themes created before.
4. Relocating and relabeling – After the transcripts were relocated into similar themes, new themes are identified. All these themes are then relabelled.

5. Reorganizing the themes and subthemes – the newly labeled themes are reorganized and sub-themes are created. The relationship between each theme and subthemes are identified.

Because of the relatively small number of interviews and FGIs, the Thematic Analysis was done using Microsoft Word (Macro enabled) as well as Microsoft Excel. All the analysis were done in the original language of interviews and Focus Group Interviews. But when reported, only then it would be translated into The English language.

4.8.4 Data Saturation

The data gathered from analysis of previous interviews are constantly compared with the next interviews. These steps are continued until we found that the concept started to repeat itself. For this purposes, interviews are spaced out to allow adequate time to transcribe the recordings and identify the themes. In this study, we decided to interview all the nine participants, but significant number of the participants shared the same concept of refusing to work even after 7^{th} interviews. This method of 'constant comparison and concept saturation' was introduced by Boeije (Boeije 2002).

4.8.5 Validity and Reliability

The number of individual interviews and FGIs conducted were based on the data saturation. We decided to stop conducting interviews as we felt that data saturation had reached. In other words, we had achieved enough data to be analyzed and there was no new information gathered from the interviews (Walker 2011, O'Reilly and Parker 2012). Data saturation had to be reached to ensure the validity of the data.

In order to ensure the validity and reliability, data collected from the Individual Interviews and Focus Group Interviews (FGIs) were analyzed separately. These two sets of data are then triangulated and checked against each other to increase the validity and reliability of the data (Bogdan and Biklen 2006). However, being the sole primary investigator, both data collected from the Individual interviews and Focus group interviews are analysed by same investigator.

However, to enhance reliability, during themes relocation, and relabeling, two investigators met at the end of the interviews and discussed the themes and subthemes generated from data. The two investigators also discuss on the relationship between the result from the part 1 of the study and the findings from the part 2 of the study. There is potential bias arising from both investigators which serve as limitation of this study.

4.9 Ethical Consideration

This research requires approval by several independent bodies:

1. Research and Ethics Committee, Department of Psychological Medicine, University of Malaya Medical Centre (UMMC)
2. National Medical Research Register (NMRR)

Permission to recruit and assess patients in the supported employment program will be obtained from the Director of Hospital Permai, Johor Bahru. The confidentiality of the study subjects will be assured and informed consent will be taken from each of them.

To prevent 'dual role', researcher and treating clinician, the researcher would not be involved in the management of the research subjects. This is to prevent the possibility of authority figure that might arouse. The patients are reminded and reassured that they can leave the study at any time and this won't affect managements of their illness.

CHAPTER 5

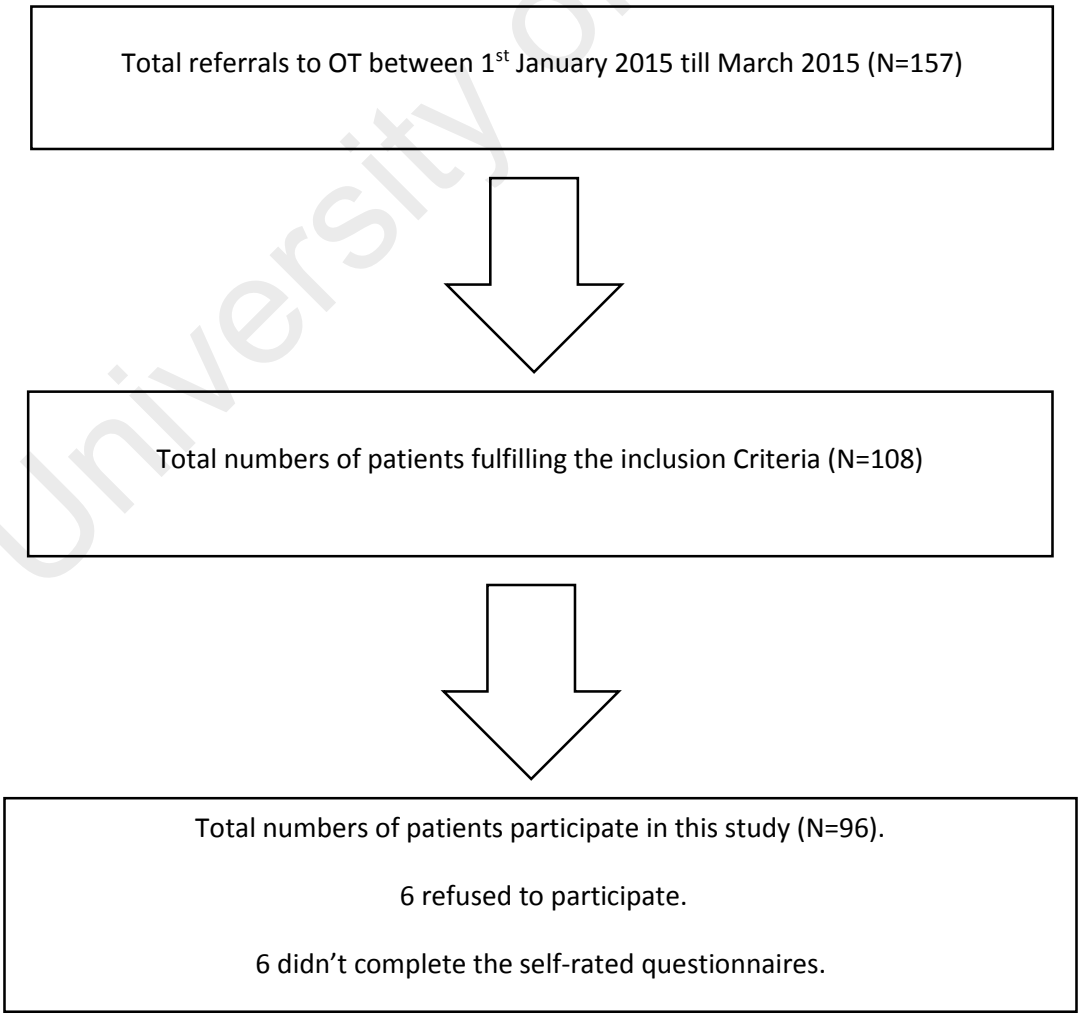
RESULTS AND FINDINGS

5.1 Part One: Quantitative

5.1.1 Study Participants

Within the 3 months from 1st January 2015 to 31st March 2015, a total of 157 patients were referred to Occupational Therapist for Supported Employment. However, only 108 fulfilled the inclusion criteria and invited for the study. This left a total of 108 patients that met the criteria. However, 6 of the patients refused to participate in the study leaving only 102 participants. Another 6 participants didn't fill the questionnaires completely and thus was excluded. This left a total of 96 participants in Part 1 of study.

Figure 5.1 Study Participants Flow Chart



5.1.2 Descriptive Statistics

a. Socio-demographics Characteristics of the Participants

Table 5.1 Characteristics of the participants (N=96)

Participants' Characteristics		Mean (SD)	N(%)
Age (years)		37.2 (10.1)	
Gender			
	Male		74 (77.1%)
	Female		22 (22.9%)
Ethnicity			
	Malay		52 (54.2%)
	Chinese		36 (37.5%)
	Indian		8 (8.3%)
	Others		0 (0.0%)
Religion			
	Muslim		53 (55.2%)
	Buddhism		33 (34.4%)
	Christianity		2 (2.1%)
	Hinduism		8 (8.3%)
Marital Status			
	Single		86 (89.6%)
	Married		5 (5.2%)
	Divorced		4 (4.2%)
	Widowed		1 (1.0%)
Education Level			
	No Formal Schooling		1 (1.0%)
	Primary School		14 (14.6%)
	Secondary School		73 (76.0%)
	Tertiary		8 (8.3%)

N = number of participants, 5 = percentage, SD = Standard Deviation

From the 96 participants. Details of the socio-demographic characteristics of participants are shown above in Table 5.1. The mean age of participants is 37.2 years old. We have more male (77.1%) than female (22.9%) participating in our study. The ethnic distribution is Malay (54.2%), Chinese (37.5%) and Indian (8.4%). This reflected Malaysia population ethnic distribution. With regards to religion, it is similar to ethnic distribution where 55.2% are Muslim, 34.4% are Buddhist, 2.1% are Christian and finally 8.3% are Hindu. The majority of the participants are single (89.6%). Divorced and widowed make up a total of 5.2%, whereas another 5.2% are married. In other words, those referred to Supported Employment Program are largely single, divorced or widowed totaling 94.8%. 76.0% of our participants finished secondary school, 14.6% only finished primary school and 8.3% completed tertiary education. 1 participant never had any formal schooling before.

b. Employment Characteristics of the Participants

Table 5.2 Employment Characteristics of the Participants

Employment Characteristics	Mean (SD)	Median (IQR)	N(%)
Numbers of Previous Jobs	6.55 (9.06)	4.00 (5)	
Longest Job (months)	27.31 (37.87)	12.00 (33)	
Duration of unemployment (months)	22.33 (48.43)	5.00 (23)	
Status of employment			
Agreed to work			73 (76.0%)
Refused to work			23 (24.0%)

SD = Standard Deviation, IQR = Interquartile Range (right skewed), N = number of participants, % = percentage

Employment Characteristics of the study participants are summarized in Table 5.2 above. As we can see from above, 73 participants out of 96 agreed to work (76.0%) when referred for Supported Employment, whereas only 23 participants refused to work (24.0%). This reflected the high desirability to work among the participants.

c. Clinical Characteristics and Outcome of the Participants

Table 5.3 Clinical Characteristics and outcome of the Participants

Clinical Characteristics of Participants		Mean (SD)	Median (IQR)	N (%)
Duration of illness (months)		157.32 (111.78)	120.00 (180)	
Number of previous admissions		4.99 (7.29)	2.00 (5)	
History of ECT				
	Yes			12 (12.5%)
	No			84 (87.5%)
Medications group				
	Atypical			50 (52.1%)
	Typical			28 (29.2%)
	Combination			18 (18.8%)
RSES		22.53 (3.45)	23.00 (5)	
QUAD				
	QUAD (average)	1.25 (0.61)	1.25 (0.77)	
	QUAD (count)	5.24 (4.59)	4.50 (8.00)	
GASS		13.22 (10.66)	12.00 (12)	
PANSS Scores				
	Positive symptoms	10.88 (4.42)	9.00 (6)	
	Negative symptoms	13.38 (5.88)	12.00 (8)	
	General Psychopathology	24.22 (4.60)	23.00 (6)	
	Total Score	48.52 (10.75)	48.00 (15)	

SD = Standard Deviation, IQR = Interquartile Range (right skewed), N = number of participants, % = percentage, RSES = Rosenberg Self-Esteem Scale, QUAD = Questionnaire on Anticipated Discrimination, GASS = Glasgow Anti-psychotic Side-effects Scale, PANSS = Positive and Negative Symptoms Scale

Table 5.3 summarized the clinical characteristics of our participants. The median of duration of illness is 120 months or 10 years since diagnosed with Schizophrenia. Most of them had never received Electro-convulsive Therapy (ECT) before (87.5%). Slightly more than half of them are prescribed with Atypical Antipsychotics at 52.1%, and 29.2% of them received Typical Antipsychotics. About a fifth of them, 18.8%, received a combination of both.

The median score of the Rosenberg Self-esteem scale (RSES) is 23.00, translating 'normal' self-esteem. The Questionnaire on Anticipated Discrimination (QUAD)'s median scored 1.25 and the number of areas is scored at 4.50. It translated mild to moderate of anticipated discrimination with an 'average' of 4-6 areas of being anticipated discrimination. When assessing the side effects using Glasgow Anti-psychotic Side-effect Scale (GASS), a median score of 12.00 is reported. And finally, when assessing the Positive and Negative Symptoms of Schizophrenia using Positive and Negative Symptoms Scale (PANSS), a median score of 48.00 was reported.

5.1.3 Bivariate Analysis

a. Socio-demographics Variables and Employment Status

Table 5.4 Socio-demographic variables and Employment Status (N=96)

Participants' Socio-demographics		Agreed to work N(%)	Refused to work N(%)
Age (years)			
	Median (IQR)	37.00 (15)	40.00 (14)
Gender			
	Male	55 (74.3%)	19 (25.7%)
	Female	18 (81.8%)	4 (18.2%)
Ethnicity			
	Malay	39 (75.0%)	13 (25.0%)
	Chinese	27 (75.0%)	9 (25.0%)
	Indian	7 (87.5%)	1 (12.5%)
Religion			
	Muslim	40 (75.5%)	13 (24.5%)
	Buddhism	24 (72.7%)	9 (27.3%)
	Christian	2 (100.0%)	0 (0.0%)
	Hindu	7 (87.5%)	1 (12.5%)
Marital Status			
	Single	65 (75.6%)	21 (24.4%)
	Married	4 (80.0%)	1 (20.0%)
	Divorced	3 (75.0%)	1 (25.0%)
	Widowed	1 (100.0%)	0 (0.0%)
Education Level			
	No Formal Schooling	0 (0.0%)	1 (100.0%)
	Primary School	12 (85.7%)	2 (14.3%)
	Secondary School	57 (78.1%)	16 (21.9%)
	Tertiary	4 (50.0%)	4 (50.0%)

N = number of participants, % = percentage, IQR = Interquartile Range

Table 5.4 shows a comparison between two groups of participants namely those ‘agreed to work’ and ‘refused to work’ in term of social-demographic variables. It showed the prevalence of employment status between gender, ethnic, religion, marital status and education level.

Table 5.5 Socio-demographic variables and Employment Status from Bivariate Analysis (N=96).

Participants' Socio-demographics		N	Agreed to work N(%)	Refused to work N(%)	X^2 Statistic (df)	P value
Age (years)						
	Median (IQR)		37.00 (15)	40.00 (14)	Z=-0.889[a]	0.374
Gender						
	Male	74	55 (74.3%)	19 (25.7%)	0.52[b] (1)	0.470
	Female	22	18 (81.8%)	4 (18.2%)		
Ethnicity						
	Malay	52	39 (75.0%)	13 (25.0%)	0.68[b] (1)	0.795
	Non-Malay	46	34 (77.3%)	10 (22.7%)		
Religion						
	Muslim	53	40 (75.5%)	13 (24.5%)	0.02[b] (1)	0.885
	Non-Muslim	43	33 (76.7%)	10 (23.3%)		
Marital Status						
	Single/Divorced/ Widowed	91	69 (75.8%)	22 (24.2%)		0.655[c]
	Married	5	4 (80.0%)	1 (20.0%)		
Education Level						
	>Primary School	81	61(75.3%)	20 (24.7%)		0.492[c]
	≤Primary School	15	12 (80.0%)	3 (20.0%)		

N = number of participants, % = percentage, IQR = Interquartile Range, Z = Z statistic, df = degree of freedom, a = Mann-Whitney test, b = Chi-square test for independence, c = Fisher's Exact Test for independence

Summary of bivariate analysis are displayed in Table 5.5. It showed that the prevalence of working status between male and female are not significantly different (P=0.470). Therefore, there is no association between gender and working status. There is also no significant difference (P=0.795) between Malay and Non-Malay. When comparing

religion in term of ‘Muslim’ and ‘Non-Muslim’, it was also found to be not significant at P=0.885.

Fisher’s Exact Test for independence was used for ‘Marital Status’ and ‘Education Level’ because ‘Expected cell’ assumption is not met despite combining groups. Nonetheless, it shows that the prevalence of both ‘Marital Status’ and ‘Working status’ are not significantly different at P=0.655 and P=0.492 respectively.

b. Employment Characteristics and Employment Status

Table 5.6 Employment Characteristics and Employment Status from Bivariate Analysis (N=96)

Employment Characteristics	Agreed to Work N=73 Median (IQR)	Refused to work N=23 Median (IQR)	Z statistic[a]	P value
Numbers of Previous Jobs	5.00 (6)	3.00 (2)	-2.476	0.013*
Longest Job (months)	13.00 (33)	12.00 (22)	-0.039	0.969
Duration of unemployment (months)	4.00 (22)	24.00 (32)	-2.799	0.005*

N = number of participants, IQR = Interquartile Range, a = Mann-Whitney test

Mann-Whitney test as the non-parametric test is used because the sample size of the 'refusal to work' group is less than 30, and normality assumption is not satisfied (skewed to right). The two median 'Numbers of previous Jobs' are significantly different (P=0.013). The two medians of 'Longest Job' are not significantly different (P=0.969). And the two medians of 'Duration of unemployment' are significantly different (P=0.005).

c. **Clinical Variables and Employment Status**

Table 5.7 Clinical Variables and Employment Status from Bivariate Analysis (N=96)

Clinical Characteristics		Agreed to Work N=73 Median (IQR)	Refused to work N=23 Median (IQR)	Z statistic[a]	P value
Duration of illness (months)		132.00 (180)	120.00 (144)	-0.211	0.833
Number of previous admissions		3.00 (6)	1.00 (4)	-2.083	0.037*
History of ECT					
	Yes, N(%)	10 (83.3%)	2 (16.7%)		0.725[b]
	No, N(%)	63 (75.0%)	21 (25.0%)		
Medications group					
	Atypical N(%)	38 (76.0%)	12 (24.0%)	1.44 (2)[c]	0.487[d]
	Typical N(%)	23 (82.1%)	5 (17.9%)		
	Combination N(%)	12 (66.7%)	6 (33.3%)		
RSES		23.00 (5)	23.00 (4)	-0.605	0.545
QUAD					
	QUAD (average)	1.21 (0.75)	1.36 (0.71)	-0.611	0.541
	QUAD (count)	4.00 (8)	5.00 (8)	-0.956	0.339
GASS		12.00 (12)	11.00 (11)	-1.118	0.264
PANSS Scores					
	Total	48.00 (15)	48.00 (11)	-0.631	0.528
	Positive symptoms	10.00 (7)	9.00 (5)	-0.733	0.464
	Negative symptoms	12.00 (9)	14.00 (11)	-1.964	0.049*
	General Psychopathology	23.00 (7)	23.00 (6)	-0.327	0.743

N = number of participants, % = percentage, a = Mann-Whitney test, b = Fisher's Exact Test for independence, c = X^2 statistic (df), d = Chi-square test for independence

In this Table 5.7 only the two medians of 'Number of previous Admissions' as well as 'Negative Symptoms score of PANSS' are significantly difference at P=0.037 and P=0.049 respectively. The rest of the variables compared among the two groups (agreed to work and refused to work) are found to be not significant.

5.1.4 Logistic Regression Analysis

Table 5.8 Variables and Employment Status that are significant at Bivariate Analysis. (N=96)

Variables	Agreed to Work N=73 Median (IQR)	Refused to work N=23 Median (IQR)	Z Statistic[a]	P value
Number of previous admissions	3.00 (6)	1.00 (4)	-2.083	0.037*
Numbers of Previous Jobs	5.00 (6)	3.00 (2)	-2.476	0.013*
Duration of unemployment (months)	4.00 (22)	24.00 (32)	-2.799	0.005*
Negative symptoms	12.00 (9)	14.00 (11)	-1.964	0.049*

N = number of participants, IQR = Interquartile Range, a = Mann-Whitney test

Table 5.8 simply summarized the variables that are found to be significant during bivariate analysis. The variables are 'Number of Previous Admissions', 'Numbers of Previous Jobs', 'Duration of Unemployment', and 'Negative Symptoms'.

Table 5.9 Predictors of Job Refusal from the binary logistic regression analysis.

Variables	Work N=73 Median (IQR)	Refused N=23 Median (IQR)	OR	95% CI of OR	P value
Number of previous admissions	3.00 (6)	1.00 (4)	0.988	0.904 - 1.080	0.789
Number of previous jobs	5.00 (6)	3.00 (2)	0.865	0.712 - 1.051	0.146
Duration of unemployment (months)	4.00 (22)	24.00 (32)	1.018	1.002 - 1.035	0.031*
Negative Symptoms (PANSS)	12.00 (9)	14.00 (11)	1.051	0.968 - 1.142	0.234

N = number of participants, IQR = Interquartile Range, OR = Odds Ratio, CI = Confidence Interval

Table 5.9 are variables entered into a stepwise logistic regression model to predict Job refusal. When these variable; Number of previous admissions, Number of previous jobs, Duration of unemployment and Negative Symptoms of PANSS, are compared and controlled in binary stepwise logistic regression analysis, only 'Duration of unemployment' remains significant at P=0.031. The regression model also returned OR of 1.018 with 95% Confidence Interval of 1.002 – 1.035.

5.2 Part Two: Qualitative

5.2.1 Themes

This study uses 'Deductive Research Approach' or 'Theory-Driven Approach'(Hayes 1997). From the literature reviews and results from Part 1, some Themes are created before Part 2 of study as a guide. But these themes are constantly reviewed and relabeled during each interviews and analysis. The basic themes developed before the interviews are as follows:

- Cognitive impairment secondary to Schizophrenia.
- Stigma from public.
- Motivational deficits.
- Performance Anxiety.
- External barrier from family, community and employer.

These themes are later expanded and reorganized after discussion with supervisors. More subthemes are created as the interviews progressed.

5.2.2 Study Participants in Individual Interviews

From the Part 1 of the study, total of 19 participants that refused to work were identified and contacted. However, only 8 of the participants agreed to come for individual interviews. Two are unreachable by phone and 4 of them quote distance of travel as a reason for not able to participate. Three of them could not come because of problem with transportation and distance. The remaining two participants agreed to come for the individual interview but eventually did not turn up, despite reminder a day before. Total of 9 individual interviews were carried out and two focus group interviews were done. The 9 individual interviews consist of 8 patients and 1 family (mother) of the patient.

The social-demographics details of the participants (patients) are as below, Table 5.10, Table 5.11, Table 5.12, and Table 5.13.

Table 5.10. Characteristics of the Participants of Part 2 of study (N=9)

Socio-demographics / Participants	Age	Gender	Ethnic	Religion	Marital Status	Education Level
P1	41	Male	Chinese	Buddhist	Single	Tertiary
P2	54	Female	Chinese	Christian	Divorced	Secondary
P3	33	Female	Chinese	Buddhist	Single	Secondary
P4	56	Female	Chinese	Buddhist	Divorced	Secondary
P5	19	Male	Chinese	Buddhist	Single	Secondary
P6*	49	Female	Chinese	Buddhist	Married	Secondary
P7	29	Male	Malay	Muslim	Single	Primary
P8	27	Male	Malay	Muslim	Single	Secondary
P9	31	Male	Indian	Hindu	Single	Secondary

N = number of participants

*Family member of P5

Table 5.11 Clinical Characteristic of the Participants of Part 2 of study (N=9)				
Clinical Characteristics / Participants	**Duration of illness (months)**	**Number of Previous admissions**	**History of ECT**	**Antipsychotics group**
P1	144	0	No	Atypical
P2	216	3	No	Atypical
P3	84	3	No	Combined
P4	372	3	Yes	Atypical
P5	24	0	No	Atypical
P6*	/	/	/	/
P7	96	4	No	Typical
P8	84	3	No	Atypical
P9	36	3	Yes	Combined

*Family member to P5

N = number of participants

Table 5.12 Clinical Characteristic of the Participants of Part 2 of study (N=9)

Clinical / Subject	RSES	QUAD (average)	QUAD (count)	GASS	PANSS (Positive)	PANSS (Negative)	PANSS (General)	PANSS (Total)
P1	25	1.00	0	5	9	10	23	42
P2	16	0.00	0	6	7	9	18	34
P3	22	1.93	13	10	7	7	17	31
P4	24	1.07	1	16	11	16	18	45
P5	24	1.29	4	13	9	9	19	37
P6*	/	/	/	/	/	/	/	/
P7	24	1.43	6	9	9	13	18	40
P8	23	1.43	8	24	11	8	17	36
P9	21	1.07	1	29	10	9	25	44

*Family member to P5
N = number of participants
N = number of participants, RSES = Rosenberg Self-Esteem Scale, QUAD = Questionnaire on Anticipated Discrimination, GASS = Glasgow Anti-psychotic Side-effects Scale, PANSS = Positive and Negative Symptoms Scale

Table 5.13 Employment Characteristic of the Participants of Part 2 of study (N=9)

Employment Characteristic / Participants	Number of previous jobs	Longest Jobs (Months)	Duration of unemployment (Months)
P1	3	108	12
P2	1	36	36
P3	5	24	15
P4	1	24	60
P5	1	<1	10
P6*	/	/	/
P7	2	<1	48
P8	2	2	12
P9	7	24	1

*Family member to P5

N = number of participants

5.2.3 Employment Specialists Participating in Focus Group Interviews

13 Employment Specialists were invited for this Focus Group interviews. Their Characteristics are summarized as below (Table 5.14):

Table 5.14 Characteristic of Employment Specialist participating in Focus Group Interviews. (N=13)

Groups	No.	Age (years)	Gender (male/female)	Duration of working as Occupational therapist (months)	Duration of working with Psychiatric Patients (months)	Duration of working as Employment Specialists (months)
F1	1	33	Male	136	118	106
	2	29	Male	53	53	3
	3	29	Male	74	74	74
	4	23	Male	9	9	3
	5	26	Female	54	14	14
	6	28	Female	53	53	12
F2	7	44	Male	236	236	59
	8	30	Male	14	10	3
	9	26	Female	54	54	24
	10	28	Female	65	23	23
	11	34	Female	100	7	7
	12	31	Female	100	7	4
	13	27	Male	44	44	44

N = Number of Employment Specialists

5.2.4 Desirability of Working

Most of the patients interviewed have a history of working before, and they express the satisfaction of work before. They appreciated the benefit of working such as the monetary income (N=7). For example, some of them said:

P2:做工当然好。要买什么都可以买。 要吃什么都可以买好吃的来吃。

(Translation: Of course working if better. You can buy whatever you want. You can buy food that you like to eat)

P7: Happy kut. Saya pernah kerja, happy. Masa dapat duit itu happy.

(Translation: Feel Happy? I worked before, happy. When you get money, you feel happy.)

The Employment Specialist also seemed to agree those patients are motivated by the income:

Focus Group: "Pesakit ini motivated dengan gaji."

(Translation: These patients are motivated by the salary)

Another patient expressed that by working she felt happier and have better esteem of herself (N=5):

P2: 以前做工很好。要买什么都能买。 又不会给人看不起。

(Translation: When I was working, I am able to buy things. And won't be looked down by others)

There are also who express 'sense of independent' when working (N=5). And also the confident that it come with as well as the ability to help support the family and repay them.

P2:自己做工不用靠人家。

(Translation: By working, I don't need to depend on family)

P5: 好处。帮人家。帮我的恩人。恩人。。。。很难讲。

(Translation: Benefits. Help others, help those who helped me before…)

The benefits of working to the patients are also seen by the Employment specialists:

F1: ..bila bekerja, dari segi activity daily living dia pun bagus….Jadi saya Nampak bila dia kerja ini, aktiviti dan routine harian ini berjadual…kita boleh Nampak dari segi perubahan dia, behavoiur dia, cara dia cakap, social dia, …

(Translation:..when working, his activities of daily livings become better…I saw him working, his activities and daily routine is more scheduled…we saw beneficial changes in his behaviours, the way he talks, socializes….)

5.2.5 Biological Factors

a. Nature and Nurture of Schizophrenia

i. Cognitive Deficit Secondary to Schizophrenia

Cognitive impairment is associated with Schizophrenia. Patients are noted to have difficulties in focusing, concentration, as well as 'memory', are the most often quoted impaired performances (N=7). As illustrations:

P1: Like when I see everything. Information come so fast I cannot process

P7: …Saya kena ambil order. Kena fikir lagi. Pasal air, pasal makan. Itu pasal saya berhenti. Susah la..Pegang buku, pegang pen. Kalau orang ramai, susah la, tak tulis, tak fikir lagi. Susah mahu ikut.

(Translation: ..I had to take order. Need to think. About drinks, about food. That's why I stopped. Difficult. Hold book, hold pen. If there is many people, difficult, can't write, can't think, difficult to follow..)

These cognitive deficits are frequently associated with certain anxieties suffered. These call for reason to refuse to work. For example:

P7: Takut la. Takut saya tak boleh buat kerja itu. Takut saya tak larat nak buat kerja itu.

(Translation: I am scared, I am scared I can't do the task. I am scared I can't do the work.)

ii. Side effects of Medications

Medication is still the primary stay of management for people with schizophrenia. However, it comes with its own side effects profiles. Some (N=4) still complain about the medications prescribed to them. The commonest complaints are drowsiness and body weakness. For examples:

*P3: **那个**晚上我吃了 EPILIM CHRONO 1500 **号，我起来小便，整个人好像**晕倒，撞那个墙壁。哪里可以开这样重的药给我喔。。**吃了很幸苦。**头晕。很像很难起身。半夜起来小便，好像要跌倒。*

(Translation: That night, after I took Epilim Chrono 1.5g, I woke up to pass urine, I felt like fainting and hit the wall. How can they (doctor) prescribe me such medications? After taking it, dizzy, difficult to wake up. Especially middle of night when waking up to pass urine, felt like falling down.)

Having said so, most patients are able to tolerate with the side effects with proper dosage adjustment, management, and support. With proper support, most patients are able to continue working. As an illustration:

FG1: kadang kadang eps berlaku juga dekat tempat kerja.. Dia kerja. Majikan jadi takut la. Dia kerja sebagai waiter, tangan dia macam keras, mata naik atas. Majikan takut, customer pun takut, waktu itu kita memang datang on the spot. Tapi waktu itu kita datang dengan seorang doctor. Team cpu, lepas bagi ubat artane, memang sudah ok. Patient itu kekal kerja.

(Translation: Sometimes Extrapyramidal Side Effect (EPSE) happens at work…he was working. The employer got frightened. He was working as a waiter. His hands become stiff and his eyes looked up. Both employers and customers got frightened. We came with a doctor and CPU team. After given Artane (benzhexol), he becomes ok. He continued to work.)

5.2.6 Psychological factors

a. Lack of Motivation

i. Easily Contented

All of the patients interviewed expressed satisfaction with their needs (N=8). It seems that all of them have their needs filled. As an example:

P8: ..Saya Cuma makan makan minum dekat rumah.. dekat rumah.. akak bagi. Dia belikan makan, saya makan. Dia beli, saya makan, saya minum. Tak ada bagi duit. Sebab dia pun kerja susah.

(Translation: I just eat and drink at home. At home, sister provides. She bought food, I ate. She bought, I eat and drink. Didn't give me money, because her work is difficult.)

Most ES at FGI found that with adequate or minimal financial support from the family, the patient would felt that they don't need to work to survive. The family usually gives in to their demand as well either out of sympathy or due to threats they gave. As illustrations:

F2: …tak boleh la , saya memang tak boleh kerja. Saya dah selesa macam ini. Bila saya Tanya duit macam mana….Dia jawab: 'tak apa mak saya ada lagi. Kalau dia meninggal pun, dia ada harta untuk saya.'

(Translation: cannot la, I can' t work. I am comfortable like this. When I ask him 'but there's no money? And he will reply 'it's ok, I still got mother, if she passes away, she has inheritance for me.')

F1: biasanya family akan support. Macam yang ada family member yang ramai, kakak tak dapat, minta abang, abang tak dapat, minta adik. Kalau taka da, dia buat hal la. Supaya dia dapat.

(Translation: Usually family will support. For those with large family, if sister didn't give, ask from brother, if brother not giving, ask for younger brother. If still no one willing to give (money), patient will threaten to create trouble. All these is so that he gets (money).)

ii. Lack of Drive

There are a lack of drive in participants interviewed (N=5). They prefer to do nothing leading a sedentary life. There have no plans for future or think about employment. As an illustration:

P8: Saya hisap sekotak sehari. Saya duduk depan rumah, duduk duduk, hisap hisap rokok.
(Translation: I smoke one pack of cigarette a day. I sat in front of the house. Sat down and smoke.)

F1: Apa yang saya Nampak, dia Memang tak terfikir untuk bekerja pun. Mungkin.. ada seorang patient ini memang seronok duduk rumah saja. Agaknya dekat rumah, dia boleh tengok tv, boleh buat apa.. dia langsung tak minat pasal kerja.

(Translation: what I saw, he does not even thought of working. Maybe he enjoyed sitting at home. Maybe at home he can watch TV and does anything. He has no interest in work.)

b. Anxiety

i. Stigma – Internal and External

The one that experienced by all the patients interviewed are a stigma. They shared their experienced of stigma either by previous employers or co-workers (N=8). For instance, one of the patients felt that he won't get employed because of having 'mental illness':

P1: But I think cannot la. Errm. That's the main reasons. Errm. Ppl.. errm because I got this sickness.

Another patient felt that he is 'ABNORMAL' (N=2). And that he was being looked down by the public which he address as 'NORMAL' people.

*P5: **我**认为是咯。我有找到。NORMAL **人看眼光高。***

(Translation: I felt so. I found jobs actually. But 'Normal people' are more discerning)

A family member of participants also addressed patient himself as '这种人' (Translate: 'this type of people').

There are also patients who had a fear of going to public because he felt that the society is afraid of him (N=3). The society is afraid of their 'aggressiveness' which is associated with their 'mental illnesses'.

P7: Takut. Sebab saya sakit mental. Orang itu takut dengan saya sebab saya sakit mental. Yalah. Takut saya marah dia. Saya tak ada marah dia.

(Translation: Am afraid. Because I am mentally ill. Those people are scared of me because I am mentally ill. Scared that I angry with him. I didn't angry with him.)

P8: Ada orang nak pukul. Kawan la. Dia tengok saya, saya ini macam orang gila. Kawan sekerja la.

(Translation: There are people wanting to hit me. My friend. He looked at me, as if I am 'insane'. My co-workers.)

Some of the patients interviewed also felt that being mentally-ill is the reason they are not favored in employment (N=6). Hence, they prefer not to let their employer knows about their mental illnesses especially at the interviews.

(Q: do you think you find a job?) *P1: But I think cannot la. Errm. That's the main reason. because I got this sickness.*

(Q: Are they not employing you because you are mental patient?) P5: 我觉得自己不是，可是别人这样讲。我就不知道是不是。自己觉得不是.

(Translation: I felt I am not. But other people said so. Then, I am not sure if I am (Mentally ill). I felt I am not(mentally ill).)

From Focus Group Interview (FGI), most of the Employment Specialist (ES) agreed that psychiatric patients experienced stigma during searching for jobs. From their experiences, stigma towards mentally ill is more prominent in a rural area compared to urban area. It is illustrated as below:

F1: …Stigma kawasan bandar persepsi masyarakat, mereka boleh terima pesakit untuk bekerja. Tetapi untuk kawasan kulai, kawasan yang kampung macam Kelapa Sawit, Sedenak, Kota Tinggi.. stigma dia orang.. yang rasa patient tak boleh bekerja.

(Translation: Stigma at urban area, society's perception, they still can accept patient to work, but rural area such as "Kulai" or villages such as "Kelapa Sawit", "Sedenak", "Kota Tinggi", their stigma…felt patient are not able to work.)

The ESs even had difficulty introducing themselves as staffs from a mental hospital to some employers. Some employers even rejected the patient upon knowing that he/she are psychiatric patients. These are illustrated as below:

F2: kalau kita jumpa majikan pun, sebab kita sebut hospital permai, stigma dia; tak ada kerja kosong. Jadi kita kata: agensi pekerjaan…Kalau agensi pekerjaan, dia cakap ada…

(Translation: when we met with employers, and we mentioned 'Hospital Permai', their reply (stigma): "no vacancy for work"… But if we introduced ourselves as 'Working Agency', they replied: "Yes (vacancy for work)".)

F1: ..Sebab setengah majikan bila masih interview, pesakit itu ok. Tapi bila bagi tahu yang patient ini patient psychiatry dia akan macam 'psychiatry, boleh kah'…patient ok, majikan terima tapi bila Su bagi tahu 'kami dari hosp permai, majikan pula banyak questioning, lepas itu dia pun tak nak'.

(Translation:… some employers when still interviewing.. the patient is ok.. But when knew that he's psychiatric patient, he asked 'Psychiatry? Is that ok?'. Patient is ok, the employer accepted him but when Su (ES) told that 'we are from Hospital Permai, the employer asked a lot of questions, in the end, he refused to accept'..)

Because of this stigma either experienced or anticipated, some patients had decided not to reveal their illness during interviews.

F2: letak patient dekat tempat kerja. Patient memang request kita tak nak majikan tahu dia PSY.

(Translation: ..tried to place patient at work, patient requested for us not to reveal to employer that he is psychiatric patient..)

However, it was also noted that with proper psychoeducation, most employers are able to accept the patient as their workers. This illustrates the importance of educating public and creating awareness about the psychiatric patients. As an illustration:

F2: .....Environment not patient friendly. Stigma itu pun ada. Kadang orang layan (pesakit) macam 'second class'. Differently. Tak nak berbual dengan pesakit. Ada juga, tapi tak banyak. Saya pernah handle kes macam itu. Jadi kita offer majikan kita punya PROKEM team tentang condition patient, how to deal if patient stress semua la. Majikan itu masih ambil la. Bila orang faham itu, isu itu takada la.....

(Translation:..environment is not patient's friendly. There is stigma. Sometimes people treat patients as 'second class'. Differently. Refused to talk with patient. There is, but not many. I had handle cases like this: when we offer employer our PROKEM (Psycho-education) about patient's condition, how to deal if patient's felt stress, etc.. the employer still accept them. When people understood, there's no issue..)

ii. Subpar Work Performance

Half of the patients interviewed noted decreased in work performance after suffering from Schizophrenia (N=4). They found that the task was harder compare as before. They had difficulty adapting to a new task and hence performed poorly at previous jobs.

P9: 最后一份工。。忘记绑螺丝。给老板炒鱿鱼。 FOREMAN。。 MECHANIC 工。

(Translation: Last Job.. I forgot to tighten a nut. Got fired by the boss. Foreman, mechanic)

Even the family of the patient interviewed also noted that her son the patient had difficulty in concentration and was not able to do a complex task. Therefore, she felt that he would not be able to work properly. She revealed:

P6: 有些。。。要比较简单的工作。复杂工作，他不可以。你看他。。。不专心的。

(Translation: some..need to be simple task. Complicated task, he can't. look at him…he can't concentrate)

FGI with ES revealed that some of the employer also noted the impaired performance of the patients. Some complained that they have difficulty in 'planning' and 'adapting' to a new task. As a result, the work performance is not on par with employers' expectation.

F1: kalau basic thing memang dia akan buat. Tapi bila hujung tahun, akan ada kiraan barang baru, dan kiraan stok, jadi bila tiba itu, patient tak boleh buat. Majikan pun rasa patient ini tak boleh bekerja.

(Translation: if basic task, he can do. But reached year end, if new stocks came, suddenly the patient unable to do. Employer will feel this patient can't work)

F2: ada yang cepat lupa. Saya pernah dengar majikan yang pesakit tak boleh nak ingat susunan barang, harga, then dia kena sentiasa ada orang tengok dia. Supervisor kena sentiasa ada di situ.

(Translation: some forget easily. I heard from employer that the patient can't remember how to arrange things, price, then he need to be supervised. Supervisor need to be there all time)

iii. Fear of Relapse

Schizophrenia is a remitting and relapsing illness, especially when there are poor adherence or presence of a stressor. In fact, almost all of the patients (N=7) experienced some sort of relapse during their work.

P3: 就是讲，我的神经病一来，就不能做工。我的 GILA 啊。。来啊. 然后我扫地，有人 KACAU-KACAU，听到鬼魂在吵，所以不要做。

(Translation: That is why, when my illness come, I can't work. My 'insanity' came. When I am sweeping, there're people disturbing, heard ghost's voices, so I don't want to work.)

P9: 我暂时好像病干扰到， 所以做工有时会那SPANNER 丢。好像听到声音，被吓到， 然后丢下来。

(Translation: I felt my illness came back, so when working, I threw spanner away. Seems like hearing voices, got scared and threw it.)

There are also who started working well, but later some of them will start experiencing some sort of relapse when they are stressed or 'overworked' (N=3).

P2: 不要啦。累了我听到鬼声音啊。

(Translation: Don't want. When tired, I will hear ghost's voices.)

One of them was worried that because of this relapses, she would lose her job and later need to start searching for a job again.

P2: 怕我做，等一下做了两三天不做。 两三天不做，很多事情。。。

(Translation: I am scared. Stopped working every 2-3 days. Stopped work every 2-3 days, very troublesome..)

The ES at the FGI also noted that some patients stopped working because of relapses. This is when the support system of 'supported employment' comes into helping the patient and employers. If adequate support and education are given to the employer and patient, the patient would usually be able to sustain the work.

F2: …Tapi waktu dia sakit, biasanya majikan nampak pesakit yang psychotic macam itu, dia akan call kita dan kita akan pastikan ubat diambil. Kalau ubat ada makan, kita akan bincang dengan doctor la. Kalau majikan masih boleh terima, taklah dibuang kerja.

(Translation:..when he (Patient) is unwell, usually the employer saw psychotic patient like that. He will call us and we will make sure he took his medications. If he takes medications, we will discuss with doctor. If employer still accept these, he won't be fired..)

There are also patients, where the ES noted that despite patients still having psychotic symptoms, they are still able to perform their given task satisfactorily.

F1: ..ada patient yang masih lagi dengar suara walaupun dia dengar tengah kerja tapi dia boleh control disebabkan dia mahu kerja, dia nak hidup independent, nak sara diri, dia boleh kerja. patient itu masih sustain sekarang dah 1.5 years. Even though kadang kadan ada suara.

(Translation: there is patient who still hear voices, but even if he hears voices at work, he will control it because he wants to work, he wants to be independent, support himself, he can work and he had sustained it for 1.5 years, even though occasionally still hear voices..)

iv. Somatic Manifestation

Many patients experienced somatic symptoms (N=6). They blamed these symptoms as the cause of their 'disability'. However, when examined by medical officers in charge, there are no noted medical illnesses presences. For illustrations:

P7: Rasa macam saya tak boleh kerja la, macam saya tak boleh datang la. Macam Badan tak sihat. Lemah badan saya. Sini lemah. (pening). Ada. Pening. Pening nak jatuh, nak tumpang.

(Translation: I felt I can't work, like I can't come (for work). My body is unwell. My body is weak. . Dizzy. As if want to fall down..)

P8: Boleh jalan-jalan. Tapi macam ada rosak sedikit. Rosak…rosak sikit la. Dalam.. macam darah saya..dalam saya tak ada darah. darah saya tak lancar itu, tak lancar itu la.

(Translation: I can walk. As if damaged a little, only a little damaged. Inside…like my blood.. I don't have blood inside. My blood flow is not smooth.)

Some of the ES at FGI found that the longer the patients remain unemployed, the more somatic complaints they have. And often these are the reasons the patients quoted to them as a reason for refusing to work. For instance:

F1: Dia kata dia susah bangun pagi. Dia dah lama tak kerja. Dia cakap nanti. Dia cakap susah bangun. Sebab dia juga susah bangun tidur.

(Translation: he said that he had difficulty waking up. He hasn't been working for long time. He said wait (work). He said difficult to wake up.)

F1: sebab kebanyakkan patient ada yang dah lama tak kerja. Like 5 years never work, only sit at home, tengok tv. ..So bila dia dah kerja satu hari lapan jam, dia rasa penat. Dia tahan 3 hari, hari ke 4, dia kata sakit dari kepala sampai kaki. Tak boleh kerja.

(Translation: Because most patient has not been working for long time. For example 5 years never worked, only stayed at home watching TV…so when he needs to work for 8 hours a day, he felt tired. He lasted 3 days, on the fourth day, he said he is unwell from head to toe. Unable to work. ..)

v. Inadequate Social Skills

Some interviewees needed more help in managing themselves. They are noted to perform poorly at social skills. They had difficulty communicating with others and often prefer to be alone and hence does not had many socially meaningful friends (N=3). As an example:

P1: (quiet place job). Ah.. ok. No body. If I dun have to meet people. I just had to clean the place. Ok. If I dun have to talk to them ok. I m ok. If they leave me alone. I ok. But if I had to talk to them. I get stress up. If I had to meet them I get stress up. If nobody ah. I just do my cleaning. I ok. If had to talk to them. I get stress up. Just get stress up.

P9: 很少朋友。。如果在外面，我没有朋友过。怕人家会利用我。

(Translation: Very few friends, Outside, I never had friends. I scare people ill-treating me.)

The Employment Specialist also noted that their clients needed more help in managing their social life, such as planning for transport, communicating with their supervisors and arranging for interviews. They also found that their clients had problem making friends at work. As an illustration:

F1: ada juga yang stress dengan persekitaran. They try kerja 2-3 hari, lepas itu kawan kawan dekat situ: dia ni macam lain lain lagi, lepas itu tak nak kawan. So taka da kawan. So menyebabkan patient stress dan dia orang akan berhenti kerja.

(Translation: Some are stress with environment. They worked for 2 or 3 days, then some of their colleagues commented: "he is different". Then he had no friends. Patient become stress and will stop working.)

F2: jumpa majikan pun anxiety ada. Bila nak interview pun tak yakin.

(Translation: He felt anxious meeting employer. He didn't show any confidence at interview.)

5.2.7 Social Factors

a. Over Involvement of Family

i. Dependency on Family

Most of them had their needs fulfilled by their family members or social welfare, and one of them resorted to asking from public (N=7). Nevertheless, none of them complained of wanting more other than food, clothes, and shelter. For instance:

P9: 我的衣服人家给的。人家会给衣服和东西吃。陌生人给的。这是我的堂弟的。。。衣服他给的。吃。。有时候跟人家讨钱咯。 他们会给。

(Translation: my cloths is from my family. People will provide clothe and food. Strangers. This belongs to my cousin (patient showing his T-shirt)… the shirt is from him. Food, sometimes ask from people, they will give.)

At FGI, ES also noted the dependency of the patient to their family in term of financial support. Although this could be good in short term, but in the long term, it might become a barrier for the patient to be gainfully employed. Some family is said to be 'over-protective' towards the patients. As an example:

F1: atau parents takut dengan , over protective la. Kalau dia kerja siapa nak jaga dia, kalau dia kena pukul orang siapa nak jaga dia?

(Translation: Or parents are scared of…over protective.. If he work, who is going to look after him, if he got hit, who is taking care of him?)

F2: kebanyakkan patient yang masih kerja dan bersemangat nak kerja. Kebanyakkan patient tak ada family. Tak ada family support. Financial ada problem. They have to hidup sendiri. Dia orang memang semangat nak kerja. Bila dia drop out from one job, dalam masa yang singkat, dia akan menghubungi kita la dan kita akan cuba tolong dia asap dapatkan new job.

(Translation: most patient who are working and motivated to work, most of them don't have family. No support from family. They have a financial problem. They need to depend on themselves. These people are motivated. When they drop out from one job, within a short period, they will contact us and we will try to get him a new job.)

ii. Family as a Barrier to Employment

One of the participants (the family member) also felt that her son would not be able to be gainfully employed because of his 'mental status'. Hence, she does not allow her son to seek employment. She fears of her son being rejected. There also some who felt that the patient would bring trouble to them.

P6: 他这种，你们带他去找工作。老板会知道吗？如果跟他相处，他（BOSS） 也会知道的。这边有'问题的人' 找工作，都可以做啊？（Refer to mental ill）

(Translation: His type, if u all bring him for work, would the employer knows? After knowing him, the employer will found out (about his mental illness). Here, 'problematic people' looking for job, are they all able to work?)

From the FGI with ESs, they too agreed that family can sometimes be a barrier to employment and forbade the patient from working. Sometimes the stigma experienced is from the patient's family as well. Because of this stigma, some families forbade the patients to go for work.

F1: Dan dia takut masa kerja patient akan curi barang barang ke dan akan kena pukul ke..atau buat benda lain. So that is why family refuse pt nak bekerja. Sama ada patient harm orang lain atau orang lain harm anak dia.

(Translation: they are worried when at work, patient will steal things and will get beaten up or cause other troubles. So, that is why family refused to allow the patient to work. Either, patient harms other or others harm their (family) child.)

Su: ada satu pt, family sendiri yang refuse pt bekerja. Sebab dia rasa pt tu untuk medication sendiri pun tak boleh ambil sendiri. Dia rasa anaknya agresif, tak boleh berdepan dengan umum lagi.

(Translation: there is a patient, his family forbade patient from working. Because they felt patient himself are not able to take his own medications. They felt their son is aggressive and unable to face the public yet.)

b. Healthcare services

i. Stigma from healthcare professionals

From both the FGI, the ESs tend to form opinion regarding patients even before they tried to help patient with their job. Some already form negative opinion towards patients' ability to work even before they started searching for jobs. Some addressed patient as 'normal' and 'not normal', which could be a form of labeling and stigma.

F1: ..dalam program ini, saya Nampak dulu, macam dulu saya pilih pesakit. Kita nampak pesakit ini semuanya bagus, fikir dia boleh kerja...

(Translation: …in this program, last time I will choose patient. We see this patient if he is good and able to work…)

F2: Kalau boleh kita nak masa interview, masa dia bekerja, nak dia as normal as possible. Kita pun confident majikan pun ok.

(Translation:..when we are reaching interview day, when at work, we expect him to be as 'normal' as possible. We will then be confident, the employer will be more acceptable..)

F2: ..dia tak boleh up to the level nak jadi cikgu, kita bagi dia sinar jernih keh..atau kerja second choice. Jadi mungkin tak sesuai dengan dia, dia tak lama. Bukan kita tak boleh cari, kita boleh cari. Tapi condition dia sendiri yang tak sampai level untuk dia kerja…

(Translation: He is not up to the level of being a teacher, we offer him sinar jernih (cleaner). But maybe he doesn't like it and won't work long. It's not we can't find, we can find, but his condition not up to par..)

c. Barriers from society

i. Stigma from employers

Many employers are still stigmatized with people with mental illness. They have negative opinion about them and are doubted their performance and capability and subsequently chose not to employ them.

F2: Sebab setengah majikan bila masih interview, pesakit itu ok. Tapi bila bagi tahu yang patient ini patient psychiatry dia akan macam 'psychiatry, boleh kah'….

(Translation: ..some of the employer when interview, patient is ok. But when get to know patient is psychiatric patient, he will ask 'Psychiatry? Is he OK?'..)

F2: …majikan terima tapi bila su bagi tahu 'kami dari hosp permai, majikan pula banyak questioning, lepas itu dia pun tak nak' . ..

(Translation: employer is acceptable at first, but after telling him 'we are from Hospital Permai, the employer starts questioning a lot, in the end, he rejected our patient..)

F1:.. stigma dia orang.. yang rasa patient tak boleh bekerja...

(Translation: They have stigma, they felt patient can't work..)

ii. Stigma from community

Community members also avoid people with mental illness. This includes patient's co-worker or even just member of the public. Loss of support and friends at work is shown to be detrimental to their work.

F2: They try kerja 2-3 hari, lepas itu kawan kawan dekat situ: dia ni macam lain lain lagi, lepas itu tak nak kawan. So tak ada kawan. So menyebabkan patient stress dan dia orang akan berhenti kerja.

(Translation: They worked 2-3 days, then the co-worker thought: 'he looked difference', and started to avoid him. No friends, patient became stress and stopped working later..)

P7: Takut. Sebab saya sakit mental. Orang itu takut dengan saya sebab saya sakit mental. Yalah. Takut saya marah dia. Saya tak ada.

(Translation: I am scared. Because I have mental illness. People are afraid of me because I have mental illness. They feared of me getting angry, but I didn't)

5.2.8 Summary of Themes

Table 5.15 Summary of Themes

Core Themes	Main Themes	Sub Themes
• Biological Factors	• Nature and Nurture of Schizophrenia	• Cognitive deficit secondary to schizophrenia • Side effect of medications
• Psychological Factors	• Lack of Motivation	• Easily contented • Lack of drive
	• Anxiety	• Stigma-Internal and External • Subpar work performance • Fear of relapse • Somatic Symptoms • Inadequate social skills
• Social Factors	• Over-involvement of Family	• Dependency on Family • Family as a Barrier
	• Healthcare services	• Stigma from healthcare professionals
	• Barriers from society	• Stigma from employers • Stigma from community
• Desirability of working		

Table 5.15 Summarized the Themes (Core, Main and Sub) found from the Individual Interviews as well as the Focus Group Interviews associated with job refusal among people with schizophrenia in Hospital Permai. In our interviews, we also found that most of people with schizophrenia actually have high 'desirability of working'.

CHAPTER 6

DISCUSSION

6.1 Employment Status and Desirability to Work

Findings from this study, the prevalence of people with Schizophrenia that refused to work after referral to the Supported Employment program is 24.0%, whereas as many as 76.0% wanted to work. The 2014 statistic from Hospital Permai's Supported Employment Program however showed that 7.7% of their referrals refused to work and this is not consistent with what this study found. One of the possible reasons for this inconsistency is the inclusion criteria of this study which include only people with Schizophrenia, whereas the 2014 statistic from Hospital Permai includes all psychiatric diagnosis. There are more people with schizophrenia refusing to work when compared to the sufferer of other psychiatric illnesses. Other studies (Marwaha and Johnson 2004, Kilian and Becker 2007) also showed that employment rate of people with schizophrenia is lower than other vocational disabilities. Before the commencement of this study, the Employment Specialists are briefed regarding the term of 'job refusal', as mentioned above, and hence they are able to identify more patients who are refusing to work as well as those avoiding work and interviews by rejecting them. Hence, this could also explain the other possibility of higher prevalence found in this study (24%) compared to the census in 2014 (7.7%).

Unfortunately studies that look into Job Refusal among people with schizophrenia are lacking locally and perhaps internationally, therefore, there are no other studies to compare with. Another limitation of this study is the small sample size due to limited resources (time constraints and budget). If the study duration was longer with larger sample size, the results might have been different.

The high percentage of 76% of participants that agreed to work upon referral is consistent with the findings of the Part 2 of the study, where it showed that most people with Schizophrenia actually have high desirably to be employed. Studies (Hatfield, Huxley et al. 1992, Reker and Eikelmann 1997) also suggested that most of the people with mental illness said that they want to work. The findings from Part 2 of the study also showed that most patients once enjoyed working and appreciate the benefits of employment that it comes with.

At times, even with the desirability to work, the patients might meet with barrier from the mental health professional themselves as our part 2 study found. For example, they might not even be referred to IPS Supported employment, because the treating clinicians felt that they are unwell or not suitable to work. Some clinicians felt that as long as the patients are still suffering from positive and negative symptoms of schizophrenia, the patients won't be able to work. Perhaps it is the low employment rate of schizophrenia of 20-30% that caused some of the healthcare professionals to have perception that people with schizophrenia are unable to work or can only achieve low level of function because of the chronicity of their illness (Harding and Zahniser 1994).

There are also occasions where, it is the Employment Specialists who felt that the patients are still unwell to work. Some might even felt that they won't be able to work independently as our findings in the part 2 revealed. All this continue to act as a barrier for people to gain employment. Sadly studies had shown that it is sometimes people with most knowledge about mental illness (such as, psychiatrist, mental health nurses) that hold strong stigmatizing beliefs about mental disorders themselves (Schlosberg 1993, Caldwell and Jorm 2001). However, somewhat contradicting, there is another study reporting that prejudice from the medical profession happened; some healthcare professionals including medical students agree that psychiatric patients are 'not easy to like'. But this study also showed that the more they understand about the illness, the less

they stigmatize (Buchanan and Bhugra 1992). Though a wide range of beliefs may arise from same group of people, it is generally accepted that psycho-education and increase in contact with people with mental illness, reduces stigma against them. In this Part 2 of study, Employment Specialists shared at Focus Group Interview, how psycho-education helped in reducing the stigma of the employers towards mentally ill patients. This highlighted the importance of psycho-education in reducing stigma, both experienced and anticipated.

6.2 Duration of Unemployment as a Predictor of Job Refusal

Through logistic regression, only one variable stand significant which is 'Duration of unemployment' at P=0.031, with OR of 1.018 and 95% CI of 1.002-1.035. It can be translated that with every increase of 1 month of unemployment there is a 1.8% increase of risk of people with schizophrenia refusing to work. However, as this is a cross-sectional study, it can only be concluded that there is an association between 'duration of unemployment' and employment status. It was not able to confirm the causal relationship between them. Nonetheless, this result from Part 1 is consistent with the findings Part 2 of study, where it was found that the longer the patient are not working it is more difficult for them to start working again. They have more anxieties and hence the avoidance about starting a new job. The part 2 of the study also postulated that it would be more physically demanding for them to start work after a longer period of sedentary, hence, the somatic complaints are commonly given as a reason for refusing or not able to work. There are also findings from the Part 2 of the study where patients avoid interviews by not answering calls from Employment Specialists or simply asked to delay job search to a later date (avoidance).

6.3 Clinical and Employment Characteristics

The bivariate analysis in Part 1, 'Negative symptoms', 'Number of previous admissions' and 'Numbers of Previous Jobs' showed significant association with the two groups of participants namely those 'agreed to work' and 'refused to work'. However, after adjusting the confounders, they are found to be insignificant variables. The confounders adjusted are Number of previous admissions, Number of previous jobs and Negative Symptoms of PANSS. Consistent with the findings of this study, the study (Yildirim, Alantar et al. 2014) also found no association between number of hospitalization and employment status. This suggested that schizophrenic symptoms including positive and negative symptoms are not significantly associated with the employment status of this study. These findings are consistent with other studies, for example, (Green, Kern et al. 2000, Midin, Razali et al. 2011). Part 2 of this study also concluded that some of the patients are still able to work despite still having positive symptoms. We also postulated that psychological factors played a more important factor in Job refusal among people with schizophrenia in Hospital Permai than the symptoms of schizophrenia.

6.4 Biological Factors: Relating Biological Factors with Psychological Factors

Part 1 of the study also found that when comparing the two groups of patients the 'agree to work' and the 'refused to work', the clinical characteristic namely; anticipated discrimination, the medication side effects, the self-esteem, the positive symptoms and the general psychopathological of schizophrenia are both identical. In other words, both groups of participants are identical in term of the clinical characteristics mentioned above, except for the negative symptoms of schizophrenia measured with 'The Positive and Negative Syndrome Scale (PANSS)' which was significant at P=0.049. However, after controlling it with other confounders such as employment and clinical characteristics, it was found to be a non-significant variable. These results from Part 1 is consistent with

other studies (Midin, Razali et al. 2011, Yildirim, Alantar et al. 2014) done before. This could mean that the negative symptoms items such as 'Poor Rapport', 'Passive/apathetic Social Withdrawal', as well as 'Lack of Spontaneity & Flow of conversation' could actually be due to the anxiety that the participants felt. The anxieties could have cause social avoidance among these people which the clinicians perceived as a social withdrawal of the negative symptoms of schizophrenia. There are also studies which relate lack of motivation and social withdrawal as part of negative symptoms of schizophrenia (Nakagami, Xie et al. 2008, Gard, Fisher et al. 2009).

Numerous studies had shown the association of cognitive impairment with schizophrenia (Dickinson and Harvey 2009, Mesholam-Gately, Giuliano et al. 2009, Rajji, Ismail et al. 2009). Impaired cognition is further associated with decreased functional outcome (Green 2006). Part 2 of the study showed that most participants of the study had difficulty in maintaining work performance as a result of impaired cognition. Unfortunately, one of the limitations of this study is the lack of exploring the association between cognitive deficit and employment status quantitatively. However a local study (Midin, Razali et al. 2011) had shown an association between cognitive functions (specifically information processing speed, executive functioning, attention and short-term verbal memory) with employment status (employed and unemployed). Observation from Part 2 of study further implied that one of the reasons for job refusal is the due to the poor work performance secondary to impaired cognitive functions. And this poor work performance might have caused certain anxieties in the participants and hence the avoidance of working. We postulated that this performance anxiety is a factor in job refusal among out study's participants.

In fact, a study has shown that social anxiety is commonly presence in people with schizophrenia, as high as 36.3%(Pallanti, Quercioli et al. 2004). The study also showed

that 51.3% of schizophrenia patients had, at least, one anxiety disorder. This showed that anxiety disorder is a significant cause of disability in people with schizophrenia.

Anxiety is also prevalent among participants who were stigmatized or anticipating discrimination. All of the patients (N=8) interviewed had experienced stigma from previous work experience and are actively anticipating discrimination. This study also found that anxiety due to stigma is associated with job refusal among people with schizophrenia. Although, from Part 1 of the study, both groups (agreed to work and refused to work) rated similarly on 'Questionnaire on Anticipated Discrimination (QUAD)', but Part 2 of the study suggested that most of the participants had internalized this stigma and projected it as anxiety. Hence, we proposed that one of the factors of job refusal is the anxiety developed from the processing of internalized stigma. As discussed above at Chapter 2: Literature Review, we understand the relation between stigma and self-esteem. But the results from the Part 1 of the study failed to recognize lowered self-esteem and anticipated discrimination of the participants. The results also showed that there are no significant differences between the two groups of a participant in term of self-esteem and anticipated stigma. This could be due to the design of the 'self-rated questionnaires' where participants might be answering 'what they want to be' instead of 'what they are feeling'. It could also be the participants trying to answer the questionnaires according to what the interviewers want. Nevertheless, another possible explanation is how the stigma experienced was processed to anxieties. There have been theories that individuals experiencing self-stigma will have diminished self-esteem or self-efficacy (Ritsher and Phelan 2004, Watson, Corrigan et al. 2007, Yap and Jorm 2011). However, it was later found that perceptions of discrimination did not predict a reduction in self-esteem (Corrigan and Watson 2002). The study further shows that only when stigma was referred to own-self, will it have an impact on self-esteem (Ritsher and Phelan 2004, Corrigan, Watson et al. 2006). In Part 1 of this study, both groups rated

similarly in term of self-esteem using Rosenberg Self-Esteem Scale (RSES), Median (IQR)=23.0(5), which translated as normal self-esteem (Rosenberg 1965). This could be due to the fact, the participants in this study does not refer the stigma to themselves. This is consistent with the findings of Part 2, where the interviewees often felt that it is the employer or public that viewed them as 'abnormal'.

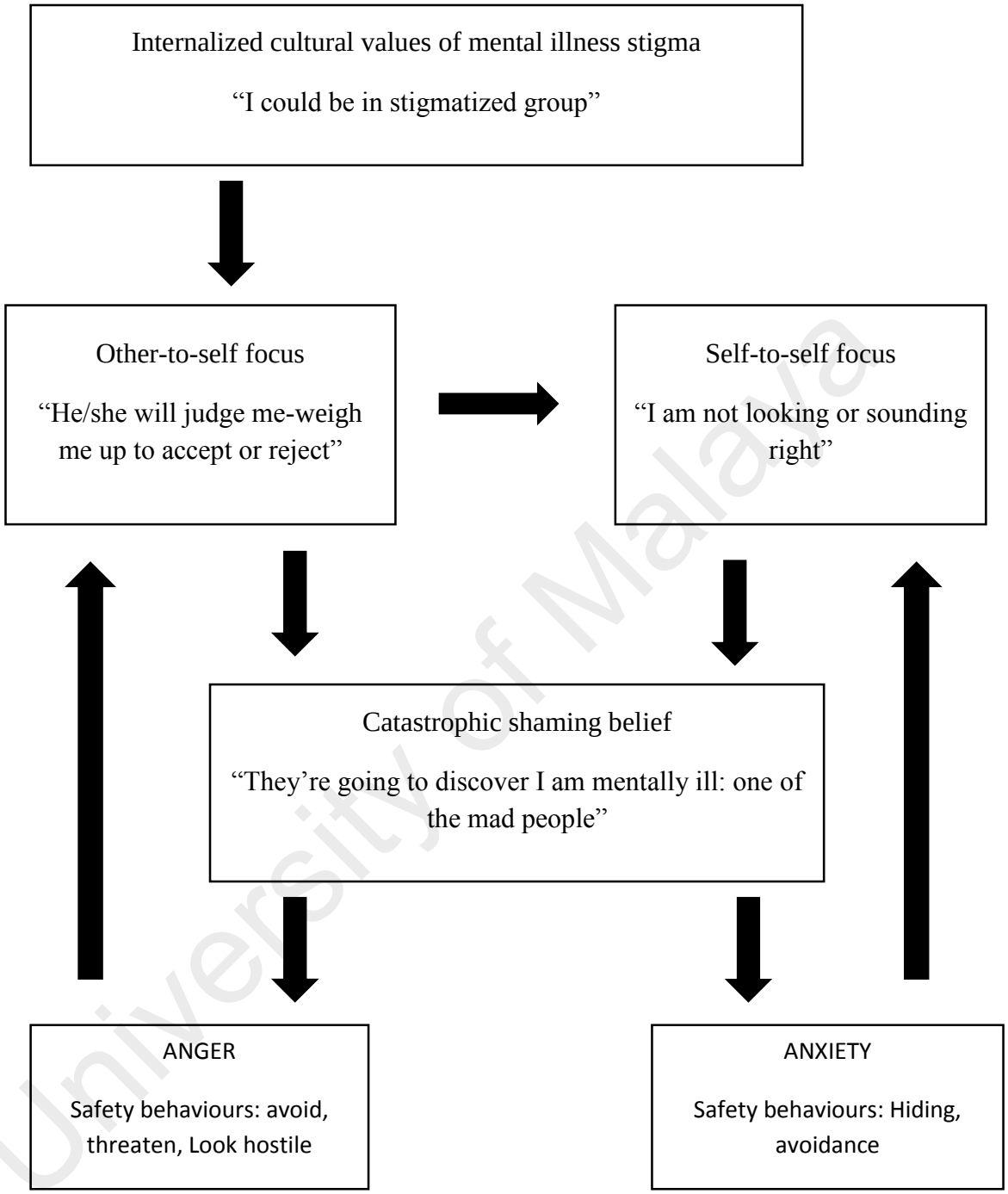
This study also found a high prevalence of external stigma or discrimination of society and even family members towards the people with schizophrenia. We also found that general populations who are stigmatized towards people with mental illness, including employers as well as healthcare professionals acted as a barrier to employment. Some clinicians did not refer their patients for supported employment because they felt that they are unfit to work. There are also employment specialist who judged too early their client not able to work and hence delayed the process of job searching and prolong the duration of unemployment. This form of external stigma has been socially defined where the mentally ill are often associated with 'aggressive, dirty, unintelligence, insincere and worthless' (Ahmed and Viswanathan 1984). Historical people with mental illness was associated with black magic, witchcraft and thus are 'cursed' and dangerous to be with. Later, these groups of people with mental illness were all confined in an asylum or mental institute. This isolation from society was viewed as to 'protect' the society from the harm by people with mental illness. To make things worse, the social media's reporting of 'high profile' crime such as homicide by mentally ill worsen the fear of public towards the mentally ill. There are also movies which project the 'negative' side of people with mental illness. This further reinforced the society belief that mentally ill people are unsafe and thus, created more rejection and avoidance of mentally ill by the public. In a survey of over 1700 adults in the United Kingdom, a study found that (1) the most commonly held belief was that people with mental illness were dangerous – especially those with schizophrenia, alcohol and Substance use dependence, (2) society also believed that some

mental disorder such as eating disorders and substance abuse were self-perpetrated, and (3) public believed that people with mental illness were generally difficult to talk to (Crisp, Gelder et al. 2000). This creates more discrimination of society towards people with mental illness and hence less contact with them. Unfortunately, our medical model also played a role in stigmatizing this group of people. By giving them a diagnosis, clinicians effectively labelled them as 'abnormal' or simply 'different' from the rest (society). Also coupled with traditional belief of the clinicians that people with mental illness are not able to function meaningfully, this further divides apart the people with mental illness from the society and reducing contact among each other. Hence, by reducing contact, this will worsen self-stigma of the people with mental illness and hence worsening their anxiety.

A good description of how Stigma generates anxiety was proposed by using a "stigma processing model" which was first proposed by (Gilbert, Birchwood et al. 2001) and later further elaborated by Birchwood (2007). In summary, it proposed how patients experiencing stigma become aware of social attitudes towards mentally-ill. They will then develop 'fear' of being located and judged. This 'fear' will then transform into safety behavior

similar to anxiety (avoidance and hiding). This model could explain how participants in this study refused to work, which are actually a safety behavior developed due to stigmatization, i.e. avoidance from public and society. Below is the flow diagram (Birchwood, Trower et al. 2007):

Figure 6.1 Stigma Processing Model



Most of these negative perceptions towards the mentally ill are found to be more prominent in the rural than urban areas as found by this study. Our study found that it is more difficult for our people with severe mental illness to be gainfully employed in the rural are compare with an urban area. This is somewhat consistent with a study which found that patients living in a small town anticipated stigmatization more frequently than

those living in the city (Angermeyer, Beck et al. 2004). It is therefore postulated this lack of psycho-education and awareness of the public towards the mental ill is the cause of both internal and external stigma. Another possible explanation is the closely knitted community structure of the rural area, where they usually function to solidify an "in" group by distinguishing people from an "out" group. In other words, they simply reject the 'abnormal' (mentally ill) from their 'normal' group. This further highlighted the importance of community mental health services where the focus is managing the patients in their own community, hence reducing rejection and at the same time reducing stigmatization both experienced and anticipated.

6.5 Managing Side effects of Antipsychotics

Antipsychotics are the mainstay of the management of people with schizophrenia. It, however, comes with its own side effects, commonly reported are Extrapyramidal side effects and drowsiness. Part 1 of this study found that the median of participants of the study measured with Glasgow Anti-psychotics Side-effect Scale (GASS) is 12.0 with IQR 12. This value lies within the range of 'absent or mild side effects' (Waddell and Taylor 2008). And when comparing both groups (agreed to work and refused to work), they appear to be similar in term of side-effect experienced. The finding of Part 2 seems to agree with results of Part 1, this showed that, with proper management and dosage adjustment, most side effects from anti-psychotics experienced are minimal and acceptable. With adequate support from Employment Specialist and Community Psychiatric Unit, the patients are usually able to be gainfully employed and was able to sustain being employed.

6.6 Psychological factors: Anxiety and Poor Social Skills Associated with Job Refusal

As discussed above, performance anxiety due to impaired cognitive function, as well as anxiety due to stigma processing. On top of that, the evidence of high prevalence of anxiety disorders or symptoms among schizophrenia coupled with findings of this study, it could be postulated that anxiety, regardless of cause, are associated or even predictor of job refusal among people with schizophrenia.

If we go back half a century ago, Elliott Jaques in 1955 put up a theory of Social Defense Theory. His theory was about how social systems are formed and acted as a defense against anxieties (Jaques 1955). This theory in line with Family System theory forwarded by Bowen, who hypothesize that the functioning of people with schizophrenia was related to the interactions of the other members of their families (Bowen 1966). Understanding these two theories, it is interesting to note how similarly people with schizophrenia and their family members interact with one another and how some tend to 'withdrawn' from society as a 'protection' from anxieties this illness had caused whether directly or indirectly. Understandably with every change (in this context, getting a job), it is actually a new journey into the unknown, and this unknown journey with unpredictable future events is a recognizable anxiety-provoking events. This led us to understand why people with schizophrenia avoided work and why their caregivers forbade them to leave home and work outside. In summary, in order to ward off anxieties they experienced either from stigma or cognitive deficit they had, they form a social defense involving a closely knitted family system.

It is also known fact that people with schizophrenia experienced cognitive deficit particularly working memory. Although it had been shown and evidenced that people with schizophrenia suffered cognitive impairment (Dickinson and Harvey 2009), perhaps directly due to brain pathology, it is arguable that this impairment could be due to anxiety

as well. A study (Eysenck, MacLeod et al. 1987) found that anxiety can affect the functioning of central executive and attentional system of working memory. This could explain how the participants in Part 2 of this study are having anxiety and difficulty with memory.

Contradictorily, a study looking at social anxiety and social functioning, they did not find any association between social anxiety and functioning, but they found an association between functioning and Negative symptoms (Voges and Addington 2005). However, it could be argued that their sample size involves only 60 patients only and consist of only those with the first episode of psychosis. Nonetheless, there is a study which showed that anxiety if unmanaged and untreated can affect functioning as evidenced by a previous study (Schonfeld, Verboncoeur et al. 1997). The same study found that the impact of untreated anxiety disorders and major depressive disorder on functioning was comparable to the effects of medical conditions. Though, this study does not involved people with Schizophrenia. Perhaps more researches are needed in future to explore the association between anxiety and employment among people with schizophrenia.

The cognitive impairment suffered by people with schizophrenia is stipulated to be related to impairment of social cognitive capacity for mental state attribution. This impairment was thought to cause poor social skills in people with schizophrenia. Some study associate this impairment with negative symptoms of schizophrenia (Brüne, Schaub et al. 2011). This poor social skill has also been found to be related to unemployment (Rutman 1994, Marwaha and Johnson 2004). In Part 2 of this study, we too found that most of the participants interviewed had difficulty in interaction and communicating meaningfully with others. This was evidenced by not turning up for interviews as promised or failure to return or answer calls. They are also found to not able to make friends. The Employment Specialists also agreed that people with schizophrenia are more 'dependent' and need their assistance to search for jobs and arrange for interviews. Some patient might

have found this to be too ‘tedious’ and hence chose avoidance. This could explain how they use rejected job search as an avoidance to prevent all this social skill inadequacy.

6.7 Social factors: Relating Social and Psychological Factors

Traditionally, Southeast Asians including Malaysia tend to have a large extended family, usually up to three or four generations living together under the same roof (VanDeusen 1980). It is a Malaysian culture as well that the family is an individual’s religious, economic, political, and social core. There is also obligation attached to each member of the family (Morrow 1989). This obligation attached simply means that members must care for each other. In this study, we found that one of the reasons for refusal to work by our participants is because of over-involvement of the family in patients’ life. Simply put, even without work which generates income as basics need to survive, the family of the patients will continue to supply the needs of the patient. A study by Ameresha in 2012 suggested this ‘need to provide’ by the family is due to the guilt feelings that the parents of child developed because of their child illness (Amaresha and Venkatasubramanian 2012). Because of this guilt, the family become over involved in the patients’ life and tried to ‘make things better’ for them. Unfortunately, in the long term, this caused the patients to lose their survival skills and become over-dependent on the family. This loss of survival skill further adds anxieties to the patient when they had to perform. This is consistent with the findings of Part 2, where over-dependence or over-protective of the patient’s family acted as a reason for job refusal for our patients. We also found that there is also a family of a patient who forbade the patient from working. And due to the over-dependence nature of the patients to their family, they would usually abide their family demand. Again, this could be in support of ‘Social Defense Theory’ and prevention of anxieties forwarded above.

When most of the patients' needs are met and supplied for, the patient lacked the drive to work to earn income to supply their own needs. They failed to appreciate the needs to work and be independent. Some researchers also argue that this lack of motivation was due to a deficit in people with schizophrenia (Fervaha, Foussias et al. 2014). He further showed that this motivational deficit will further inhibit functional recovery of the patients. From the findings of our study, we proposed that with this motivational deficit coupled with the over-protective nature of the patients' family, is a factor for Job refusal. Future research perhaps will try to find an association between family involvements as a motivational deficit of the people with schizophrenia.

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CHAPTER 7

STRENGTHS AND LIMITATIONS

7.1 Strength

- Mixed method sequential explanatory design is designed to fill in any 'research gap' that quantitative studies lacked.
- This design also enables the Part 2 of study to explain or clarify the results from the Part 1 of the study.
- All participants were interviewed personally in a separate room to ensure privacy.
- All participants are allowed adequate time and privacy when answering the self-rated questionnaires.
- Self-rated questionnaires are designed for easy understanding and allow the participants to answer truthfully.
- >90% questionnaires were answered and completed.
- Self-rated questionnaires (QUAD and GASS) are translated into the Malay and Chinese language; this allows more people to participate in this study.
- Self-rated questionnaires (RSES) are available in both Malay and Chinese and had been validated.
- The interviewees in Part 2 of the study consist of patients, patient's family as well as Employment Specialists. This allows triangulation and validation of the data.
- The findings of this study provide a baseline data for future research into the field.

7.2 Limitation

7.2.1 General

- The cross-sectional design of this study is a limitation. Data was taken at a point in time limiting its observations.
- Due to the nature of the cross-sectional study, it was not able to determine causation in the results obtained.
- Samples obtained from a mental hospital. This is not representative of the Malaysian population.
- The numbers of self-rated questionnaires and clinician-rated scales might be too time-consuming for some participants.
- The self-rated questionnaires might not have been answered truthfully by the participants. The participants might be answering 'what they hope they are' instead of 'what they are experiencing'.
- The numbers of interviewees interviewed might not be adequate to achieve saturation of data.
- There are potential bias and influence during formulation of the themes and subthemes by the two different investigators.

7.2.2 Specific

- Calculation of sample size done in Part 1 of study larger precision of d=10% might not be precise enough.
- Sample size might be inadequate due to the limitation of the duration of the study.
- The purposive sampling method is used in Part 2 of study, which might cause bias.
- A single investigator, limiting the number of samples obtained in a single session.

- Duration of illness data was collected via subject self-reporting and may result in recall or comprehension bias.
- The way the individual and focus group interviews are conducted by investigators who are also the clinician might cause 'authority figure', where they interviewees might not be answering truthfully enough.
- Data from individual interviews might not be rich enough due to lack of dynamic interaction as those from Focus Group Interviews.
- The thematic analysis may miss nuanced data.
- The flexibility of the Part 2 of study (Qualitative) makes it difficult to concentrate on what aspect of the data to focus on.
- Discovery and verification of themes and codes are meshed together, causing difficulty in interpretation.
- Limited interpretive power if analysis excludes theoretical framework.
- A single investigator who does the transcribing, translation, coding and thematic analysis might cause bias and also reduced the reliability of data collected.

CHAPTER 8

RECOMMENDATION

Several limitations had been mentioned above. This study could have been done with longer study period to capture more subjects. Ideally, where budget allows, there should be a different person in conducting the interviews, transcribing, translation and checking the transcripts, to ensure the better reliability of the data. There should also be preferably two or more investigators to do the coding and thematic analysis to enhance validity and also reduces bias.

Some of the patients might have rejected Supported Employment even before referrals from referring centers namely Outpatient Department, Wards, District Hospitals or 'Klinik Kesihatan' (District Health Clinics). Hence, we might have missed a number of patients who actually refused to work. So, if the study was done at more referring centers, we might be able to invite more participants for this study. This will also bring us closer to representing Malaysia population.

This being first of such study locally, it mainly serve as a basis for future more conclusive research, hence a lot of limitations mainly the small sample size (Nargundkar 2003, Singh 2007). With prevalence of 24% for people with schizophrenia refusing to work, perhaps in future study, using this estimate of proportion and higher precision of d=0.05, larger sample size can be calculated. Hence with more subjects, the results and findings might be different from this study.

The qualitative study employed by the Part 2 of this study is able to fill the gap between psychology and quantitative research. Perhaps in a future study, a more in-depth analysis than Thematic Analysis can be used, such as Discourse Analysis or Interpretative

Phenomenology Analysis. These analyzes are able to capture greater details of culture, past experiences, beliefs, morality, and imagination.

Last but not least, in a future study, using validated questionnaires will also greatly helped in increasing the validity of the similar study. Instead of using self-rated questionnaires, perhaps clinician-rated questionnaires can also be incorporated in future studies.

CHAPTER 9

CONCLUSION AND CLINICAL IMPLEMENTATION

The management of the people with schizophrenia should be holistic, addressing all Biological, Psychological and Social aspect of the patients. We have only begun to understand why people with schizophrenia refused to work. This study had discovered that there is no direct association between Job refusal and stigma, medication side effects, symptoms of schizophrenia and self-esteem of participants. The only significant association is the duration of unemployment which was explained by the Part 2 of the study that 'the change' from prolonged unemployment to employment causes heightened anxiety and hence avoidance and refusal to work. This study also found that the possible factor for job refusal is concerning with anxiety of the people with schizophrenia. Coincidentally this study also found an external barrier to employment, which was from the family.

Hence by understanding these difficulties that people with schizophrenia had in seeking employment and recover functionally, we can help them and the caregivers with our current service provision; for instance, psycho-education for both the patients and caregivers in aiding them to understand more about this deliberating illness. This will help with their anxieties and prepared them better psychologically to return to function. This study also found that people with schizophrenia lack social skills. This is consistent with other study done before (Lysaker, Bell et al. 1995); it might be the reason for them to avoid work. Social skills training had been consistently proven to help people with Schizophrenia in social functioning (Halford and Hayes 1995). So perhaps we should start incorporating such services into our management of schizophrenia.

This study also found that despite patients experiencing side effects with neuroleptic medications, but with proper management, most patients would not have any complaints

and was able to gain functionality. Thus, we should make it a routine to screen for possible side effects that our patients had and managed them promptly. Again, they should be psycho-educated about medications side-effects so that they are more prepared and gain confidence with managing themselves.

As discussed above, psycho-education or creating awareness of mental illnesses among the public as well as healthcare professionals greatly reduces their negative perception towards mentally ill. Mental Hospital and their different service teams could create public awareness via campaigns, public talks and also utilizing the social media to educate the public to reduce their stigma and discrimination. Awareness among the public and patient not only reduces stigma and discrimination but it also helps to increase the presentation of people with mental illnesses to primary health care (Eaton and Agomoh 2008).

9.1 IPS Supported Employment and Community Services

Traditional Vocational rehabilitation had been proven unsuccessful because the majority of the patients remain under sheltered workshop and inside a mental institution. Eventually, they became 'comfortable' inside the mental institution. And hence, their safety behavior (avoidance from society) due to internalizing stigma continues to be reinforced. In time, the patients will become institutionalized and this brings more ill effect to them.

Institutionalizing not only caused stripping of the identity of patients and depersonalization but also caused loss of rights and further worsen the stigma of being mentally ill. Also, by admitting to a mental hospital, the society would label him/her as psychiatric patients more readily. This labeling effectively created more external stigma towards them and further anxieties from internal stigma. This further caused them to feel rejected from society and worsen the stigma they experienced/anticipated. It had been

well recognized that institutionalizing deprives patients of social contact also known as social poverty. This isolation will further compromise their already impaired social skills, causing more difficulty for them to be de-institutionalized and gain full functional recovery later. In fact, the study had shown how the lack of independence and responsibility for patients within institutions, along with the 'depressing' and 'dehumanizing' environment, became a barrier for them to gain employment as well as living independently (Wright, Gronfein et al. 2000). This further highlighted the importance of IPS supported Employment in supporting people with mental illness to gain competitive employment in the community with the evidence above showing its benefits.

There is convincing evidence that increased contact with persons with severe mental illness is associated with lower stigma (Kolodziej and Johnson 1996). Hence, this highlighted the importance of managing the people with schizophrenia at home and the importance of community mental health services. One of the focuses of community mental health services is to treat the patients at their home. This will enable them to continue living in the community and maintaining their connection with their families, friends, work, and neighborhood. This will increase the contacts and effectively lower the stigma towards mentally ill. The community mental health services continue to support the patients' goals and strength which further aid his/her full functional recovery (Slade 2009).

In summary, there should be close collaboration between all the services in mental health service to help people with mental illness to return to function. Our aim should not only be confined to symptoms reduction but to help them to achieve full functional recovery encompassing: symptoms stability, independent living, work functioning, as well as social functioning (Kern, Glynn et al. 2009).

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