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**EXPLORING THE ROLE OF COGNITION IN
COPING OF MULTIPLE SCLEROSIS**

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2012

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**EXPLORING THE ROLE OF
COGNITION IN COPING OF
MULTIPLE SCLEROSIS**

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

August 2011

CERTIFICATE OF ORIGINALITY

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ABSTRACT

Background: The prevalence rate of multiple sclerosis (MS) has been growing in Hong Kong. Cognitive deficit is well-documented in the Western literature. However, the neurocognitive functioning profiles of Chinese suffering from MS remains unexplored. Also, much less is understood about its effect on coping and psychological adjustment in MS.

Aim: First, the current study sought to establish the preliminary profiles of cognitive functioning of Chinese persons with MS in Hong Kong. Second, it endeavored to understand the details of stressors encountered by the patients in daily lives. Third and more significantly, it aimed at exploring the roles played by different domains of cognition in coping processes and psychological outcomes in these patients.

Method: This cross-sectional study recruited 72 Chinese participants with MS in the neurology clinics of local hospitals. A mixed method of qualitative and quantitative approaches was employed. The themes of MS-induced stressors were identified by semi-structured interviews. The core quantitative method consisted of a battery of neuropsychological tests assessing verbal and visual memory, executive functioning, attention and information processing speed, psychomotor functioning, verbal fluency, as well as visuospatial ability, and several validated scales that measured coping strategies, coping resources in terms of perceived social support and illness acceptance, and psychological health - depressive symptoms and general life satisfaction.

Results: First, the participants performed comparably poorly on all cognitive tests when compared to the local norm with comparable age and education level. The effect sizes ranged from medium to large. Second, MS posed a wide range of

dramatic stressors in life such as unpredictability of illness trajectory and economic difficulties. Third, specific cognitive domains exerted influences on the choices of coping strategies. Executive functioning positively predicted the use of active problem solving. Verbal memory predicted increased use of seeking social support. Fourth, social support and illness acceptance were supported to be important in promoting better psychological adjustment even in the face of stressors. More specifically, acceptance acted as a partial mediator between subjective stressor and depression. Patients with less stressor tended to maintain greater acceptance towards the disease, which, in turn, decreased the level of depression. Lastly, path analysis informed the specific role of verbal memory in enhancing the levels of perceived social support and acceptance, which ultimately led to reduced depressive symptoms and higher satisfaction in life.

Discussion: The study was the first systematic attempt to explore the relationships among neurocognition, stress and coping in a Chinese context. Developing optimal coping is of paramount importance in the rehabilitation of a chronic illness like MS. Both executive functioning and verbal memory were found to affect the coping process. Future development of effective coping intervention for MS individuals should take the effects of cognitive deficits into serious consideration. Furthermore, apart from the use of problem-focused coping methods, the significance of coping resource like acceptance was also highlighted. Results were discussed in the context of incorporating cognitive assessment together with the management of stress and developing effective coping in the integrative care for MS for both Chinese and non-Chinese populations.

ACKNOWLEDGEMENTS

I would like to express my deepest gratitude to my chief supervisor Dr Alma Au May Lan for her extensive guidance, enlightenment, support, patience, help and encouragement throughout my study. I would also thank my co-supervisor Professor Chan Yuk Chung for his support and help.

I am indebted to many clinical professionals of the neurology outpatient clinics of the Department of Medicine in Queen Elizabeth Hospital and Pamela Youde Nethersole Eastern Hospital as well as the Department of Medicine and Geriatrics in Princess Margaret Hospital, United Christian Hospital, and Kwong Wah Hospital, especially Dr Iris Chan Wing Sze, Dr Patrick Li Chung Ki, Dr John Hiu Ming Chan, Dr Tsoi Tak Hong, Dr Lau Kwok Kwong, Dr Ng Ping Wing, Dr Hui Kwok Fai, and Dr Cheng Wing Keung for their support and generous assistance in facilitating the recruitment of patients.

It is also a pleasure to thank all the patients with multiple sclerosis who took part in this study. Without their enthusiastic participation and support, the study would not have been possible.

Last but not least, I owe my deepest gratitude to my family especially my parents Chi Wah and Wong Ying for their love, unconditional support, and encouragement.

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Chapter 1 – INTRODUCTION TO THE CURRENT STUDY

1.1 Research background

The prevalence rate of multiple sclerosis (MS) is relatively lower in Asia when compared to the Western countries. However, there has been a growing trend of MS diagnosis in Hong Kong. The prevalence rate has been increased from 0.88 (Lau et al., 2002) to 4.5 per 100, 000 (Chan, 2010, June 15) in the last decade. MS individuals suffer a huge amount of stress due to the unpredictable nature of disease and its negative impacts on daily lives (e.g. Devins & Seland, 1987; Higginson, Arnett, & Voss, 2000; Holmes, Madgwick, & Bates, 1995; Pflieger, Flachs, & Koch-Henriksen, 2010; Rao et al., 1991; Whetten-Goldstein, Sloan, Goldstein, & Kulas, 1998). It has become crucial for them to manage and respond to stress properly because stress has been found to trigger MS relapses or exacerbation (Brown et al., 2006a, 2006b; Mitsonis, Potagas, Zervas, & Sfagos, 2009; Potagas et al., 2008). As a matter of clinical concern together with a paucity of relevant empirical studies in Chinese populations, there is such a need to establish systematic and comprehensive research to study these Hong Kong Chinese individuals with MS in the contexts of neurocognitive impairments, sources of stress, and effective coping.

Among the chronic neurodegenerative diseases, MS is regarded as a more “special” form because it mainly attacks the individuals in the relatively young adulthood (approximately age of 20 to 40 years; Matthews, Acheson, Batchelor, & Weller, 1985), whereas the prevalent age onset of Parkinson’s disease and Alzheimer’s disease is after 60s (Freedman, 1990). Commonly, age from 20s to 40s

is the golden period of one's life to achieve significant life goals such as building career, marriage and establishing home, and strengthening financial status. However, MS is more likely to come to rip off the health from an adult during this golden period, resulting in disruptions in life goals, social activities, work performance, interpersonal relationship, and so forth. In addition to having difficulties in daily lives, patients also have to deal with MS itself, which is featured with a very variable progression of relapse and remission, making it impossible and hard to predict its fluctuating course. Even though patients with MS look healthy most of the times, impairments may start to happen in the sensory, motor, and cognitive domains in a subtle way. What is even worse is that there is currently no treatment for cure but only for symptomatic relief (Rao, Huber, & Bornstein, 1992). Given the devastating effects of MS on no matter physical health and psychosocial aspects, the patients are believed to suffer substantial amount of stress. Unfortunately, stress has long been considered as a trigger in MS attacks since 1890s (Mitsonis et al., 2009). A close relationship between stressful life event and MS exacerbation was documented (Brown et al., 2006a, 2006b; Potagas et al., 2008). Patients encountering more distressing events were more likely to have relapses than those not experiencing such events (Franklin, Nelson, Heaton, Burks, & Thompson, 1988). Due to the possible impact of stress on disease exacerbation, examination of factors which mitigate stress, such as coping, appears critical.

Stress seems to be an unavoidable aspect of life in the patients with MS, but what makes the difference in psychological well-being is how the patients cope with it. Successful coping indeed facilitated the adaptation to the illness regardless of the existence of stressors. In contrast, maladaptive coping in response to stressor incurred negative consequences in subjective well-being including depression, anxiety, and lower sense of life satisfaction (Ryan et al., 2007). Coping involves two

processes – cognitive appraisal of the stressor and behavioural effort to handle the stressor, also known as coping strategy (Lazarus & Folkman, 1984). A bundle of previous MS coping-related literature devoted to examining what types of coping strategies had the significant predictive power of psychological well-being of the patients (e.g. Arnett, Higginson, Voss, Randolph, & Grandey, 2002; McCabe, 2006; McCabe, McKern, & McDonald, 2004; Pakenham, 1999; Pakenham, 2001; Pakenham, 2006; Pakenham, Stewart, & Rogers, 1997; Rabinowitz & Arnett, 2009). Generally, problem-focused coping strategies have been reported to be associated with better psychological well-being (McCabe, 2006; McCabe et al., 2004; Pakenham, 1999; Pakenham, 2001; Pakenham, 2006; Rabinowitz & Arnett, 2009). On the contrary, emotion-focused coping strategies were more likely to develop depression and emotional distress (Arnett et al., 2002; McCabe, 2006; McCabe et al., 2004; Pakenham, 1999; Pakenham et al., 1997; Rabinowitz & Arnett, 2009). It gave us an impression that problem-focused coping like active coping was much more successful in alleviating the impact of stress on psychological health than emotion-focused coping. Moving beyond, it has been unclear about whether any underlying factors existed to affect the MS patients to choose a certain form of strategy over others when coping with the stressful events.

One of the possible factors which determined the coping processes in the patients was cognitive impairment. Cognitive impairment has been indicated as a common concomitant of MS, and the prevalence rates varied from 43% to 70% (Benedict, Cookfair et al., 2006; Peyser, Rao, LaRocca, & Kaplan, 1990). It can affect the patients at both earlier and later disease stages (Pelosi, Geesken, Holly, Hayward, & Blumhardt, 1997; Piras et al., 2003). Impaired cognition in MS is due to inflammatory demyelination of axons. Axonal damage or loss thus causes interference or inhibition of nerve signals transmitted along the axons. The

widespread development of lesions in the white matter leads to cognitive impairments (Benedict, Bruce et al., 2006; Benedict et al., 2004). Previously, a plenty of Western neuropsychological studies strived to examine the extent to which different domains of cognition deteriorated among the MS individuals (Benedict, Bruce et al., 2006; Benedict, Cookfair et al., 2006; Benedict, Weinstock-Guttman et al., 2004; Benedict et al., 2005; DeLuca, Barbieri-Berger, & Johnson, 1994; DeLuca, Chelune, Tulskey, Lengenfelder, & Chiaravalloti, 2004; DeLuca, Gaudino, Diamond, Christodoulou, & Engel, 1998; Duque et al., 2008; Fischer, 2001; Huijbregts et al., 2004; Nagy et al., 2006; Simioni et al., 2009). MS can result in a variety of deficits in cognitive domains that depend on the attacked brain site. Along with a recent meta-analytical work on MS-related cognitive deficits (Prakash, Snook, Lewis, Motl, & Kramer, 2008), two updated systematic reviews (Chiaravalloti & DeLuca, 2008; Ferreira, 2010) which targeted to integrate the past MS neuropsychological studies and identify the common cognitive profiles of the patients with MS also documented that long-term memory, attention and speed of information processing, executive functioning, and motor functioning were most likely vulnerable to the disease. In fact, cognitive impairment has been shown to greatly associate with functional status in MS (Higginson et al., 2000; Rao et al., 1991). The cognitive sequelae of MS exert impacts on a lot of daily activities including the ability to do housework, maintenance of employment, and making decisions. In support of this, previous research revealed that deficits in new learning caused the patients with MS to reduce the ability to make decisions, directly affecting everyday life functioning (Nagy et al., 2006). More seriously, impairments in speed of information processing (Beatty, Blanco, Wilbanks, Paul, & Hames, 1995), verbal memory (Benedict, Cookfair et al., 2006), and executive functioning (Parmenter, Shucard, & Shucard, 2007) were responsible for employment loss. It seemed apparent that individuals with MS would

encounter a certain degree of difficulties in everyday activities which required a substantial cognitive load. In light of this, it was highly speculated that their cognitive dysfunction also had an effect on their coping abilities. Notwithstanding there might be a close relationship between cognitive deficit and coping in MS, the research in this area was still in its infancy.

Cognitive area might carry a certain amount of effects on coping; for example, the ways of active planning depended on the level of executive functioning. A recent study documented that MS patients with impaired executive function tended to adopt less positive coping strategies (Goretti, Portaccio, Zipoli, Razzolini, & Amato, 2010). Furthermore, evidence for the association between cognitive impairment and coping strategy has also been provided by the research in the field of brain traumatic disease and schizophrenia (Krpan, Levine, Stuss, & Dawson, 2007; Lysaker, Bryson, Marks, Greig, & Bell, 2004; Wilder-Willis, Shear, Steffen, & Borkin, 2002). For instance, impaired visual memory was related to higher level of escape avoidance and lower degree of problem solving in the individuals with schizophrenia (Lysaker et al., 2004); better executive functioning was found to relate to greater usage of planful problem solving coping strategies (Krpan et al., 2007). Notwithstanding there was evidence suggesting that coping might partly depend on specific cognitive domains in the patients with impaired cognition, to the best of my knowledge, very limited MS coping research had taken into this into account thus far. To what extent different cognitive impairments might interfere with the choices of strategies, which in turn further impacted on psychological adjustment remained questionable.

Besides of coping strategies, sufficient coping resources are also useful in mitigating the impact of stress on psychological well-being of an individual. Coping does not only embrace individual elements, but it also involves social aspects. In MS, perceived social support has been mostly examined as a coping resource in

predicting the level of psychological distress and depression (Barnwell & Kavanagh, 1997; Chwastiak et al., 2002; Gulick, 2003; Pakenham, 1999; Ritvo, Ftsk, Archibald, Murray, & Field, 1996; Ryan et al., 2007). The results found a protective role of perceived social support in well-being. The higher degree of social support the patients with MS obtained, the better outcomes on psychological health of these patients had.

While facing the inherently uncertain and incurable nature of MS, patients' illness cognition called acceptance has become another substantial coping resource to them for maintaining good psychological well-being. By definition, illness acceptance refers to one's acknowledgement of being chronically ill, perception of own ability to live with it, and mastery of its negative consequences (Evers et al., 2001). Extracted from in-depth interviews in the qualitative research (Kirkpatrick Pinson, Ottens, & Fisher, 2009; Malcomson, Lowe-Strong, & Dunwoody, 2008), acceptance of illness was the main theme brought up by those patients coping with MS successfully in order to deal with the illness uncertainty. However, this important coping resource has been received much less attention in the past MS quantitative research. In light of this, the current study further argued that along with perceived social support, illness acceptance should also be considered as a useful coping resource contributing to positive adjustment among the MS patients under the theoretical framework. Again, how the patients perceived the amount of support from their significant others and accepted the illness might suppose to be determined partly by their cognitive resources. The current study would take the pioneering role in investigating the interaction of neurocognition with social support/ illness acceptance and psychological well-being in MS.

To recapitulate, there has been lack of systematic and empirical study in the areas of cognitive impairments, stress, coping, and psychological adjustment, and

their relationships in Chinese MS individuals in Hong Kong. The cognitive profiles and MS-related stressful experiences of Chinese MS patients have not been thoroughly examined and well-documented. More importantly, the roles played by specific cognitive deficits in influencing the coping processes including preferences of strategies and variations in perceived social support as well as illness acceptance remained unclear and warranted further detailed examination.

1.2 Objectives of the current study

Seeing that MS has become prevalent in Hong Kong, systematic research addressing the unresolved issues about the interaction between cognitive functioning, coping mechanism, and psychological well-being in a Chinese context is in need. The current study was the first systematic attempt to extensively investigate MS in Chinese populations. It not only incorporated both neurocognitive and psychosocial approaches, but it also used combined research methods. One of the primary aims was to obtain the preliminary profiles of cognitive performance of the Chinese MS persons in Hong Kong. In order to fill the knowledge gaps in the MS literature, the current study also served several purposes. Firstly, the study targeted to identify the themes of subjective stressor brought by MS in the daily lives of these patients using semi-structured interview. Secondly, the study explored relationships between stressor, coping in terms of strategies and resources, and psychological adjustment in depth under the theoretical framework. Finally, the study especially incorporated cognitive aspect into the traditional transactional stress and coping model by empirically investigating how different domains of cognition affected the relationships of perceived stress, coping, and psychological well-being.

1.3 Theoretical framework

1.3.1 The transactional model of stress and coping

Lazarus and Folkman's (1984) transactional model of stress and coping would be adopted in the current study. The model argued that stress would only exist when the demands of a situation exceeded the resources which an individual possessed. Despite the occurrence of stress, the individual did not necessarily develop unfavourable psychological outcomes such as depression. Indeed, coping took a very important role in helping the individual deal with the stressful situations. Lazarus and Folkman regarded that coping involved two components – cognitive appraisal and coping strategy. The former component referred to an evaluation of the stressful event in terms of its threat, challenge, and controllability. After the assessment, the individual would consider what behavioural efforts s/he could do to cope with this stressful event. Coping strategy (e.g. problem solving and distancing) was the action that the individual took to confront stress. Adaptive coping strategy was able to eliminate the harmful influence caused by the stress, whereas maladaptive coping strategy might incur negative psychological well-being. All in all, the ultimate goal of coping was to restore homeostasis in physical or psychological health even in the face of stressful event.

1.3.2 Modified theoretical framework in the current study

The hypothesized theoretical model in the current study which was mainly built on Lazarus and Folkman's (1984) theoretical framework was illustrated in figure 1. According to the previous findings (Goretti et al., 2010; Krpan et al., 2007; Lysaker et al., 2004; Wilder-Willis et al., 2002), the coping process such as choices of strategy was dependent of the level of cognitive functioning among the patients with cognitive deficits. Therefore, the original contribution of this hypothesized model

was to incorporate cognitive component into the transactional stress and coping model for the MS populations. There were two routes in the hypothesized model: (1) the first route followed Lazarus and Folkman's concept that stressors were linked to psychological health directly and also indirectly through coping mechanism; (2) cognitive performance of the MS persons was taken into account in the second route that it might exert influences on the preference of coping strategies and/ or perception of coping resources such as perceived social support, which ultimately affected the homeostasis of psychological health. It was believed that this modified theoretical framework could provide a more all-round approach for us to understand how the MS individuals who might suffer from cognitive impairments in selective domains (e.g. memory) adjusted their psychological states in respond to the stressors in lives.

1.3.3. Variables of interest

The current study contained independent, intervening, and dependent variables. First of all, the independent variables included stressors and cognitive performance. The stressors were divided into objective versus subjective ones. Objective stressors were composed of illness parameters which were duration of diagnosis and symptoms, severity of neurological functioning, number of recent symptoms, and frequency of relapses. On the other hand, subjective stressor was the number of MS-induced stressful events experienced by the patients. The cognitive performance of the MS patients was composed of scores obtained on a battery of neuropsychological tests assessing verbal and visual memory, executive functioning, attention and speed of information processing, psychomotor functioning, verbal fluency, and visuospatial ability. Secondly, the intervening variables relating to coping were coping strategies and coping resources. Coping strategies were defined as the behavioural ways by

which MS persons employed to deal with the MS-induced stressors in daily lives. With regard to coping resources, the current study was particularly interested in looking into the levels of perceived social support and illness acceptance. Lastly, psychological health was the dependent variable consisting of two measurements: the degrees of depressive symptoms and life satisfaction.

1.4 Outline of hypotheses

The current study hypothesized that stressors including MS itself and its related stressful experiences in daily lives would exert a significant effect on psychological health of the patients. Second, coping strategies and resources would have a mediation effect between stress and psychological health. Third, adaptive coping strategies and/ or sufficient coping resources would alleviate the negative impact of stressors on psychological health. Finally, cognitive impairments would play a significant role in changing the patients' coping processes that ultimately exert influences on psychological health.

Chapter 2 – INTRODUCTION TO MULTIPLE SCLEROSIS

2.1 Overview

Multiple sclerosis (MS) is a chronic inflammatory demyelinating disease which causes damage in the central nervous system (CNS). The site in the CNS to be affected is in random approach; indeed, this unique characteristic leads to diversity of MS-related symptoms. Not only the symptoms vary, but the illness trajectory is also different among MS patients. Three main types of MS are well recognized which are relapsing-remitting, primary progressive, and secondary progressive. Each type is featured with a unique pattern of disease course. The etiology of MS, however, remains a mystery. There is currently no medical treatment to cure but only for symptomatic relief. The age of disease onset is young adulthood, and females are more likely to be diagnosed with MS than males. There is an increasing trend of MS diagnosis in Hong Kong over the past decade. Approximately 300-400 persons in Hong Kong are found to suffer from MS (Chan, 2010, June 15). Given its unpredictable development, MS patients have to face uncertainty and unexpectation about the future in their lives.

2.2 Pathology

MS is a progressive neurodegenerative disease. It predominantly attacks the CNS which includes the brain, spinal cord, and optic nerve. Over millions of neurons in the CNS operate with each other to maintain a proper and efficient functioning in our body. A neuron consists of three main parts – cell body, dendrite and axon. Axon is the longest part in the neuron; its usefulness is to transmit nerve impulses from the

cell body to the dendrites of another neuron. Along the axon, myelin sheath, consisting of mainly fatty issue as an electrical insulator, is formed to help the nerve impulses propagate along the nerve fibre. Myelin sheath bears a very important role in the CNS to ensure the nerve signals transmit in a faster and accurate track. In MS, pathologically speaking, the immune system invades the CNS. The white blood cells mistake myelin sheath as virus and start to destroy it. In the very early stage, the affected axon area will get inflamed and progressively lose myelin sheath.

Demyelination (i.e. loss or destruction of myelin sheath) is the hallmark clinical feature of MS. It results in problematic and ineffective nerve signal transmission between the brain and other parts of the body. In fact, the name of disease “Multiple Sclerosis” refers to multiple scars on the myelin sheaths. In response to demyelination, a sclerotic lesion (also called plaque) is produced by other CNS cells around the inflamed or demyelinated sites. Active lesions appear as bright white spots under the magnetic resonance imaging.

2.3 Symptoms

The lesions lead to the emergence of diverse symptoms in MS, determining by the functioning of the affected neurons in the CNS being attacked. The symptoms are highly variable among patients, in terms of both variety and severity. Also, they can range from unobservable to noticeable level to others. These comprise optical neuritis (e.g. blurred/ double vision), motor disorder (e.g. slowness of movement, loss of balance, and tremor), sensory problems (e.g. feelings of tingling and pain and loss of sensation), bladder problem, dizziness, headache, fatigue and so on.

Furthermore, as the white matter in the brain is destructed, cognitive deficits can also be one of the early manifestations of unobservable symptoms. Prior studies have well documented that persons with MS displayed impairments in different cognitive

domain (Benedict, Cookfair et al., 2006; Foong et al., 1997; Prakash et al., 2008; Simioni et al., 2009). They showed deficits in memory (especially working and long term memory), executive functioning, attention, speed of information processing, psychomotor speed, visuospatial ability, and decision making. Again, the cognitive impairments differ from patient to patient depending on the location of lesions in the white matter.

2.4 Subtypes

Three main subtypes exist in MS which are relapsing-remitting (RRMS), primary progressive (PRMS), and secondary progressive (SPMS). They are different in the clinical course and severity. A majority of patients belong to RRMS. RRMS – patient with this subtype will have a chance to fully recover or have sequelae and residual deficit upon recovery after the occurrence of symptom(s). The disease, however, may relapse again. The times between disease relapses are featured by the absence of disease progression. PPMS – the cardinal characteristic is a progressive, nearly continuously worsening of neurological function upon the first presentation of symptom onset. There can be some minor fluctuations in disability but without discrete relapses. SPMS – its course is initially started with RR and then followed by a gradual worsening of function, with or without occasional relapses and minor remissions. It is viewed as the long-term outcome of those initially with RRMS. Regardless of which subtype, the progress of disease is unpredictable since the next location of CNS to be attacked by the immune system is unknown. There is no absolute pattern of demyelination.

2.5 Incidence

The incidence of MS is subject to change in different regions over the world. It is

proportional to the latitude (Baum & Rothschild, 1981). That means more MS cases are reported in the country where is further away from the equator than that where is closer to the equator. To exemplify, there are more than 200 diagnoses per 100, 000 inhabitants in southeast Scotland (Rothwell & Charlton, 1998), whereas less than 1 case reported in 100, 000 population from Asian countries (Wasay, Khatri, Khealani, & Sheerani, 2006). Even though MS is regarded as a rare neurological disease in China (Pugliatti, Sotgiu, & Rosati, 2002; Rosati, 2001), the prevalence rate of MS per 100, 000 has been increased from 0.77 (Lau et al., 2002) to 5.50 in Hong Kong (Chan, 2010, June 15). It may be due to higher awareness of this disease among the physicians.

Furthermore, females have higher likelihood to suffer from MS than males with a ratio of 9.6 in Hong Kong (Lau et al., 2002). The disease onset is mainly in young adulthood. In China, the mean age at MS onset was around 30 years (Cheng, Cheng, & Jiang, 2009).

2.6 Uncertainty

Given the greatly unpredictable, debilitating, and long-term nature of MS, patients have to bear a great deal of uncertainty about future such as health condition, personal achievement, employment, and interpersonal relationship. This kind of uncertainty to the patients is devastating and overwhelming. They may start to lose confidence in making any expectations in their lives. Not only the disease poses challenges on the patients' physical health, but it also adversely influences psychological well-being. Physical health-related problems such as the unpleasant symptoms, unwanted drug side effects, and increasing levels of physical disability may all adversely influence their function in daily activities such as work performance, which in turn can bring aversive emotional responses in the patients.

Together with the highly fluctuating course and lack of availability of medical indicators assuring the patients of the demyelination deterioration speed and location, this kind of unpredictability poses particular adjustment problem. When compared to patients with other chronic illness, the patients with MS, due to its inherently unpredictable nature, have to additionally make efforts to deal with “unpredictability and uncertainty” in their lives.

Chapter 3 – LITERATURE REVIEW

3.1 Overview

The devastating power of MS does not solely confine to physical health, but it also profoundly impacts on psychological well-being of patients. The patients have to make psychological adjustment to the advent of disease including its undesirable symptoms and its consequent intrusion upon social life, work performance, financial status, life goal and so forth. It was noted that some of the patients with MS had particular problems in adaptation to this highly unpredictable and fluctuating disease; nevertheless, a part of patients were less likely to experience difficulties in their psychological adjustment (de Ridder, Schreurs, & Bensing, 2000). It would further argue that changing health and other conditions in life resulting from MS may not necessarily adversely influence psychological adjustment; instead, the manner in which patients with MS cope with these changes is more critical. The transactional model of stress and coping (Lazarus & Folkman, 1984) has been the most popular framework in explaining the stress buffering effects. In MS coping-related literature, the differential predictive powers of coping strategies to psychological well-being have been well investigated. In relation to coping resources, social support has been the only resource commonly examined in the association with psychological well-being of the patients with MS. Due to this limitation, this chapter would further introduce another coping resource as seemingly important as social support in chronic diseases known as acceptance of illness. Most importantly, moving beyond the psychosocial level, neurocognitive perspective was also taken into account for influencing MS individuals' coping processes in terms of coping strategy and resource. The role played by specific cognitive domain as underlying factor in

interfering with the choices of coping strategy and perceptions of resources was examined. Because very scant previous research had been devoted to understanding this aspect, it was expected that additional examination of cognitive issue would further facilitate our deeper understanding of coping in the patients with MS.

3.2 Stress and psychological adjustment in MS

A recent MS systematic review presented that perceived stress had a link with adjustment outcomes such as depression and life satisfaction among the MS patients (Dennison, Moss-Morris, & Chalder, 2009). Evidence showed that the magnitude and significance of linkage depended on the level and type of stress. Examples of stressors were reviewed as follows.

3.2.1 *Illness parameter*

It has been well suggested that the disease itself acts as a stressor to the persons with MS. The disease duration, severity, and physical disability were the typical illness parameters to be measured; however, the results were controversial. Prior studies found that longer duration of illness were related to better adjustment (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994; Pakenham et al., 1997; Ryan et al., 2007), whereas some studies suggested that duration was unrelated to adjustment (Dennison, Moss-Morris, Silber, Galea, & Chalder, 2010; Rudick, Miller, Clough, Gragg, & Farmer, 1992; Zeldow & Pavlou, 1984). Likewise, although a few studies reported that the severity of disease reflected by neurological impairment had a positive relationship with depression (Johnson, Terrell, Sargent, & Kaufman, 2007; McIvor, Riklan, & Reznikoff, 1984; Ryan et al., 2007), others did not find such relationship (Dennison et al., 2010; Devins, Seland, Klein, Edworthy, & Saary, 1993; Devins et al., 1996; Fisk et al., 1994; Pakenham et al., 1997). Lastly, most of the

previous studies found greater physical disability to be associated with poorer psychosocial adjustment (e.g. Devins et al., 1993; Lynch, Kroencke, & Denney, 2001).

3.2.2 *Illness uncertainty*

Given the unpredictable characteristic of its development in MS, patients are in the face of a high level of uncertainty which poses stress in their lives. Illness uncertainty is conceptualized as perceptions of ambiguity and unpredictability about symptoms, diagnosis, treatment, and future plans (Mishel, 1988). In MS, uncertainty of illness was demonstrated to be significantly related to psychological adjustment. Higher uncertainty would result in worse emotion well-being including depression and distress (Lynch et al., 2001; McNulty, Livneh, & Wilson, 2004; Mullins et al., 2001; Wineman, Durand, & Steiner, 1994; Wineman, O'Brien, Nealon, & Kaskel, 1993; Wineman, Schwetz, Goodkin, & Rudick, 1996).

3.2.3 *Psychosocial stressors*

The symptoms of MS can cause disruptions in patients' daily life functioning (Higginson et al., 2000; Rao et al., 1991). Not surprisingly, people with MS find it necessary to decrease the level of paid employment as the disease progresses. Unwilling income reduction is regarded as stressful. The effects of MS result in heavy economic burden to the patients as well as their families (De Judicibus & McCabe, 2005; Holmes et al., 1995; Pflieger et al., 2010; Whetten-Goldstein et al., 1998). Financial stress led to lower subjective sense of psychological well-being in the patients (De Judicibus & McCabe, 2007; Johnson et al., 2007). Indeed, the financial stress could be magnified when the patients were in the life stage of building career, establishing a family, paying a mortgage, and educating children.

In addition to financial burden, the changing marital relationship might act as a stressor to the patients as well. Devins and Seland (1987) found that many patients with MS also experienced strained relationships as a result of stress related to the disease. Nevertheless, it was remarked that not every patient's marital relationship had been deteriorated. Hakim et al. (2000) reported that the majority of 305 patients maintained the marital relationship. Only 9% of the patients divorced after suffering from MS. Some of them described that the relationship had been improved since the MS diagnosis. McCabe, McDonald, Deeks, Vowels, and Cobain (1996) presented mixed findings as well. They found that a third of participants improved the quality of relationship with their partner, while one third found no change, and other third noted their relationship had become worse.

3.3 Theoretical framework - understanding the buffering model of stress

The inconsistent findings in the stressors have increased our awareness of the possible construct which can buffer the aversive psychological responses induced by stress. Indeed, the extent to which the stressors deteriorate psychological well-being may partly depend on the way in which the patients cope with the stressful situation such as the changing symptoms associated with the illness. In the coping literature, the transactional model of stress and coping advocated by Lazarus and Folkman (1984) has attracted considerable research attention to elucidate the interrelationship between stressor, coping, and psychological health.

According to Lazarus and Folkman (1984), coping is a dynamic process and involves two critical components: cognitive appraisal and coping strategy. When encountering a difficulty, an individual evaluates the nature of this event in terms of

threat, challenge, and controllability (primary appraisal) and then have secondary appraisal about what s/he should do to manage this difficulty. This action is known as coping strategy. Both cognitive appraisals and coping strategies influence the stress-psychological health relationship. Stress only appears when the individual appraises the difficulty which taxes or exceeds his/ her available resources; however, it does not necessarily lead to negative psychological health depending on how s/he reacts to the stress. Generally, the individual who uses adaptive coping strategies to deal with the stressor is protected from developing poor psychological health, whereas that employing maladaptive strategies is usually more likely to have negative psychological adjustment. Humans often alter their thoughts and behaviours based on the changes in their appraisals of the situations and in demands of those stressors when responding to a variety of stressful situations. This model has been successfully applied to chronic illness (Maes, Leventhal, & de Ridder, 1996), HIV/AIDS (Pakenham & Rinaldis, 2001) and MS (Pakenham, 1999) in explaining psychological distress in the patients. In light of this, using this model to explore the coping process with greater details among the patients with MS may be useful in helping us identify the predictors and/ or mediators of better psychological adjustment.

3.4 Coping in MS

3.4.1 Cognitive appraisals

Cognitive appraisal has been defined as an evaluative process which reflects an individual's subjective interpretation of an event in terms of threat, challenge, and controllability (Lazarus & Folkman, 1984). In general, the evaluation of illness-related parameters (e.g. disease severity) and events affected by the disease

(e.g. work performance) as being uncontrollable and/ or being threatening to one's well-being is more likely to lead to negative psychological adjustment to the illness. In the literature, only three studies had examined the association between cognitive appraisal of MS-related stressor and psychological well-being (Pakenham, 1999; Pakenham et al., 1997; Wineman et al., 1994). All of them claimed that appraisal of an event was related to psychological health including emotional well-being, depression, and distress after controlling for the severity of MS, although the magnitude of association varied from 6% to 29%.

3.4.2 *Coping strategies*

According to Lazarus and Folkman (1984), when confronting stressful situation, an individual employs a variety of strategies to cope with the stressor itself or consequent emotion so as to maintain psychological homeostasis. Coping theorists broadly classified coping strategies into two main streams: problem-focused and emotion-focused coping. Problem-focused coping is conceptualized as aiming at altering the source of stress, whereas emotion-focused coping is used to reduce the emotional distress elicited by the stressful event. The examples of problem-focused coping include planful problem solving and seeking social support to help. On the other hand, emotion-focused coping contains passive avoidant strategies like wishful thinking and more constructive approach like positive reappraisal of the problem.

A relatively more number of studies gauged the relationship between coping strategies and psychological adjustment outcomes in MS. Across the studies, reliance on certain emotion-focused coping strategies which were wishful thinking and escape-avoidant coping were consistently related to poorer psychological health (e.g. Arnett et al., 2002; Beatty et al., 1998; McCabe, 2006; McCabe et al., 2004; Pakenham, 1999, 2006; Pakenham et al., 1997; Rabinowitz & Arnett, 2009). In

contrast, active problem-focused strategies, seeking social support, and more adaptive emotion-focused strategies were associated with better adjustment (e.g. McCabe, 2006; McCabe et al., 2004; Pakenham, 1999; Pakenham, 2001; Pakenham, 2006; Rabinowitz & Arnett, 2009). It was noticed, however, that the strength and significance of coping strategies as correlates or predictors varied among studies. The heterogeneity in the findings might well be due to the differences in sample size and the use of coping instrument, factors controlled for in the regression analyses, and stressors or stressful contexts with reference to which patients were required to describe their coping efforts.

3.4.3 *Coping resources*

Coping resources are comparably stable characteristics of an individual's disposition and environment and refer to what is available to the individual when s/he chooses his/ her coping strategies (Moos & Billings, 1982). Social support has long been the only coping resource included in the stress-buffering model of psychological health in MS (Pakenham, 1999). Additionally, the current study would introduce another coping resource - acceptance of illness conceptualized as a belief held by the patient that also seems to be important in adaption to the chronic illness.

3.4.3.1 Social support

It has been increasingly recognizing the role of social support as a coping resource since the mid-1970s. A plenty of earlier studies argued that the sufficiency of social support had a direct association with severity of both psychological and physical symptoms and/ or acted as a mediator between stressful situations and symptoms (Andrews, Tennant, Hewson, & Vaillant, 1978; Billings & Moos, 1981; Cohen & Wills, 1985; Schaefer, Coyne, & Lazarus, 1981; Wilcox, 1981). Similarly, social

support has been identified as an important factor in adjusting to the illness among the patients with MS (Gulick, 2001; Harrison & Stuijbergen, 2006; Somerset, Sharp, & Campbell, 2002). Pakenham (1999) supported the buffering effect of social support on the psychological adjustment of the MS patients. Stressful life events did not necessarily result in poor adjustment provided that the patients had adequate perceived social support. Moreover, several studies suggested a strong inversely relationship between social support and distress (Barnwell & Kavanagh, 1997; Chwastiak et al., 2002; Gulick, 2003; Ritvo et al., 1996). Recently, Ryan et al. (2007) found perceived social support could predict the subjective well-being in terms of psychological distress and life satisfaction in the MS patients. Higher social support perceived by the patients would enhance the global sense of life satisfaction and reduce distress.

3.4.3.2 Acceptance of illness

Given the fact that MS is chronic and incurable, MS individuals have to live with it and face its detrimental effects on physical health, psychological well-being, and functional abilities for lifetime. Under some circumstances where an unchangeable and bad thing happens, it may be better and adaptive for those affected persons to accept it instead of thinking a way to deal with and/ or escape from it. In this sense, how the patients accept and integrate MS as well as the relevant inevitable, negative changes into a new life becomes a crucial topic. The concept of illness acceptance has been successfully applied to other chronic diseases such as chronic pain (McCracken & Vowles, 2008) and HIV/ AIDS (Guck, Goodman, Dobleman, Fasanya, & Tadros, 2010). By definition, illness acceptance is conceptualized as illness cognition to diminish the unfavourable meaning of the disease (Evers et al., 2001). It is a belief held by the patient who acknowledges suffering from inherently long-term

and deleterious nature chronic disease. S/he also recognizes a need to live with it as well as perceives the ability to tolerate its uncontrollable, unpredictable characteristics and to master the aversive consequences caused by the disease. Acceptance of illness does not preclude patients from making efforts to improve quality of life nor ignore the disease exacerbation, but it rather enables patients to maximize their health under the circumstances of impairment and limitation.

Earlier research provided evidence for the significant role of acceptance in patients with other chronic diseases of which the symptoms were similar to MS - uncontrollable and incurable. Van Damme and his co-workers (2006) found that patients with chronic fatigue syndrome who had higher level of acceptance of fatigue tended to have lower psychological distress and higher emotional stability. Consistently, the protective role of acceptance in promoting psychological well being has been reported in the field of chronic pain studies (McCracken, 1998; McCracken, Spertus, Janeck, Sinclair, & Wetzel, 1999; Viane et al., 2003). Acceptance of chronic pain has been demonstrated as an independent predictor of less pain, disability, and depression among the patients (McCracken & Eccleston, 2003; McCracken & Vowles, 2008). Moreover, Guck et al. (2010) also argued that illness acceptance was a significant predictor of depression, mental functioning, and physical functioning after controlling the effects of demographic and medical variables in the population of HIV/ AIDS. Those patients with HIV/ AIDS would obtain better functional outcomes when they had higher degree of acceptance towards their illness. It seems convincingly that acceptance of illness is a useful construct in promoting the psychological health in the patients living with chronic illness conditions. Previously, researchers attempted to develop and validate the scales measuring acceptance of illness in the MS patients (Evers et al., 2001; Stuifbergen, Becker, Blozis, & Beal, 2008). In the study of Evers et al. (2001), they also correlated acceptance of illness

with health outcomes. They revealed that acceptance was beneficial to both physical and psychological health in patients with MS, as indicated by a reduction in disease activity, physical complaints as well as negative mood.

Apparently, the role of illness acceptance in MS required more attention in research. A few qualitative health studies (Kirkpatrick Pinson et al., 2009; Malcomson et al., 2008) have emerged to capture the important messages from the MS patients that acceptance of the illness and living with it were the significantly protective factors to successful adaption to the illness. There has been, however, only one recent quantitative study examining the predictive power of acceptance in psychological well-being in MS individuals (Dennison et al., 2010). Acceptance was reported to contribute to better psychological health. Given that many patients and health professionals regarded that developing acceptance of disease was critical in successfully adaptation to chronic illness (Telford, Kralik, & Koch, 2006), the paucity of MS studies into acceptance arouse our need to elucidate the relationship between acceptance and psychological adjustment empirically.

3.5 Cognitive impairment and its relationship with coping in MS

3.5.1 Cognitive impairments

Cognitive impairment has been indicated as a common concomitant of MS in research since 1980s, and the prevalence rates varied from 43% to 70% (Benedict, Cookfair et al., 2006; Peyser et al., 1990). It can occur at both earlier and later disease stages (Pelosi et al., 1997; Piras et al., 2003). Impaired cognition in MS is due to inflammatory demyelination of axons, resulting in the appearance of lesions or plaques in the brain. Axonal damage or loss thus causes interference or inhibition of

nerve signals transmitted along the axons. The widespread development of lesions in the white matter leads to cognitive impairments. For instance, structural imaging using MRI revealed that the width of the third ventricle associated strongly with cognitive performance in MS (Benedict, Bruce et al., 2006; Benedict, Weinstock-Guttman et al., 2004) and provided predictive validity for cognitive status (Benedict, Bruce et al., 2006). Also, the subcortical atrophy had a higher correlation with cognition than did the whole brain atrophy or lesion load (Benedict, Carone, & Bakshi, 2004; Bermel, Bakshi, Tjoa, Puli, & Jacobs, 2002). Many Western neuropsychological studies have documented different domains of cognitive deterioration among the MS individuals (Benedict, Bruce et al., 2006; Benedict, Cookfair et al., 2006; Benedict, Weinstock-Guttman et al., 2004; Benedict et al., 2005; DeLuca et al., 1994; DeLuca et al., 2004; DeLuca et al., 1998; Duque et al., 2008; Fischer, 2001; Huijbregts et al., 2004; Nagy et al., 2006; Simioni et al., 2009). General intelligence remained intact in the patients (Macniven et al., 2008), and dementia was rare in MS (Fischer, 2001). Nonetheless, the clinical presentation of one subtle and specific deficit in cognition could vary substantially among the patients (Fischer, 2001). MS can result in a variety of deficits in cognitive domains that depends on the attacked brain site. Along with a recent meta-analytical work on MS-related cognitive deficits (Prakash et al., 2008), two updated systematic reviews which targeted to integrate the past MS neuropsychological studies and identify the common cognitive profiles of the patients with MS also documented that long-term memory, attention and speed of information processing, executive functioning, and motor functioning were most likely vulnerable to the disease (Chiaravalloti & DeLuca, 2008; Ferreira, 2010).

Long-term memory problem is one of the most consistently cognitive impairments in MS, and 40-65% of the MS patients have been affected (Rao et al.,

1993). Long-term memory refers to the capacity of learning new information and recalling this information after a certain period of time. There has been a debate on the underlying mechanism which leads to impaired memory in MS. Early research argued that the primary memory problem was the difficulty in retrieval information from the long-term storage (Caine, Bamford, Schiffer, Shoulson, & Levy, 1986; Rao, 1986; Rao, Leo, & St. Aubin-Faubert, 1989); however, recent work regarded that the problem in initial information learning was the main cause (DeLuca et al., 1994; DeLuca et al., 1998; Thornton, Raz, & Tucker, 2002). No matter which stance was correct, it was true that deficits in either learning new information or recalling the information deteriorated the memory abilities.

Information processing speed is the most common cognitive domain to be impaired in MS, even with a pronounced decline over several years of follow-up (Bergendal, Fredrikson, & Almkvist, 2007; DeLuca et al., 2004; Janculjak, Mubrin, Brinar, & Spilich, 2002). Patients were often found to have a reduced speed to process the information maintained in the brain for a short time period. Indeed, neuropsychological tests tapping speed of information processing were predictive of long-term cognitive deterioration. The Paced Auditory Serial Addition Test and the Symbol Digit Modalities Test have been supported as the most sensitive measures to screen those MS patients with cognitive decline (Parmenter, Weinstock-Guttman, Garg, Munschauer, & Benedict, 2007; Rosti, Hämäläinen, Koivisto, & Hokkanen, 2007). Both of the tests demanded on the functions of attention, working memory, and more heavily on speed of information processing. Moreover, deficit in speed of information processing was also commonly reported to occur concurrently with other impaired cognition such as working and long-term memory (Gaudino, Chiaravalloti, DeLuca, & Diamond, 2001; Janculjak et al., 2002; Lengenfelder, Chiaravalloti, Ricker, & DeLuca, 2003). The extent of memory deficit was positively correlated

with the impairment in processing speed (Archibald & Fisk, 2000; DeLuca et al., 2004; Gaudino et al., 2001). In addition, sustained attention deficit is common in MS as well (McCartney Chalk, 2007). The MS individuals were reported to perform more poorly on the cognitive tests which involved both attention and information processing speed when compared with the controls (Kujala, Portin, Revonsuo, & Ruutiainen, 1995; Olivares et al., 2005).

Executive functioning refers to the ability for goal-directed behaviour as well as adaptation to environmental demands or changes. This function is considered to be high-order cognition because it involves the abilities in planning, organizing, anticipating outcomes, and directing resources appropriately (Loring & Meador, 1999). When compared to deficits in memory and speed of information processing, executive functioning impairment were less likely to occur in MS. But still, a portion of patients have had this problem. Drew and his colleagues (2008) indicated that 17% of the patients found difficulties in different executive abilities such as inhibition, shifting, and fluency. Likewise, perseverative errors were also seen in the patients with MS (Arnett et al., 1994; Parmenter et al., 2007; Rao, Hammeke, & Speech, 1987).

Deficit in motor functioning is also reported in the patients with MS. Motor functioning is commonly assessed using the grooved pegboard and finger tapping (Prakash et al., 2008). Seeing that the lesions in the brain and spinal cord can cause a range of motor disturbances such as slower hand movement, not surprisingly, the performances on these tests of MS patients were inferior to the healthy controls.

3.5.2 Effects of cognitive deficits on coping processes

Cognitive impairment has been shown to greatly associate with functional status in MS (Higginson et al., 2000; Rao et al., 1991). The cognitive sequelae of MS exert

impacts on a lot of daily activities including the ability to do housework, maintenance of employment, and making decisions. In support of this, previous research revealed that deficits in new learning caused the patients with MS to reduce the ability to make decisions, directly affecting everyday life functioning (Nagy et al., 2006). Similarly, Kessler and his colleagues (1992) indicated that a range of memory measures accounted for significant variances in daily living activities in MS over and beyond the effects of demographic and physical disability variables; functional impairments including accomplishing household task, driving, travelling with public transportation and difficulty in going out alone were primarily associated with deficits in new learning. More seriously, several impaired cognitive domains were responsible for employment loss; for example, speed of information processing (Beatty, Blanco et al., 1995), verbal memory (Benedict, Cookfair et al., 2006), and executive functioning (Parmenter, Shucard et al., 2007). Benedict and his co-workers further provided evidence that impairments in these three cognitive domains were predictive of vocational status after controlling for the effects of age, gender, education, disease course, and depression. It seemed apparent that individuals with MS would encounter a certain degree of difficulties in everyday activities which required a substantial cognitive load. In light of this, it was highly speculated that their cognitive dysfunction also had an effect on their coping abilities.

Notwithstanding there might be a close relationship between cognitive deficit and coping in MS, the research in this area was still in its infancy. To the best of my knowledge, nonetheless, only one recent study had started to address the association between cognitive functioning and type of coping strategy in MS (Goretti et al., 2010). They found that MS patients with deficits in sustained attention and executive function tended to adopt less positive coping strategies. Other evidence supporting this association was given in the fields of schizophrenia (Lysaker et al., 2004;

Wilder-Willis et al., 2002) and traumatic brain injury (Krpan et al., 2007). Lysaker et al. (2004) argued that deficits in different cognitive domains were shown to be predictive of particular coping styles in the patients with schizophrenia. For instance, executive dysfunction was related to high level of distancing. Poorer visual memory was associated with more frequent use of escape avoidance and less planful problem solving. Poorer verbal memory had a negative relationship with seeking social support. Consistently, Wilder-Willies et al. (2002) asserted an inverse association between active coping and impairments in executive function and memory in the patient with schizophrenia. In the sample of persons with traumatic brain injury, executive function significantly contributed to the use of problem focused coping after controlling for pre-morbid intelligence and injury severity. Better executive performance was associated with greater utilization of planful problem solving coping strategies, whereas the control group did not show this pattern (Krpan et al., 2007).

To date, however, a large of prior empirical studies failed to concern the role played by cognitive impairments in coping in terms of both strategies and resources, which ultimately led to various level of psychological adjustment in MS. Until the last decade, only two studies highlighted that coping style acted as a moderator (Arnett et al., 2002; Rabinowitz & Arnett, 2009) and partial mediator (Rabinowitz & Arnett, 2009) between cognitive dysfunction and depression. Specifically, active coping protected the MS persons from developing depression in relation to their cognitive deficits. The mediational outcomes suggested that cognitive dysfunction partially led to depression because of its effects on coping strategy. In these two studies, only executive functioning was assessed. How other domains of cognitive deficits might affect the coping processes in MS remained questionable. It gained growing interest in the current study to obtain evidence to reveal the extent to which

deficits in cognition link to unsuccessful coping in the patients. As a result, this study would firstly systematically assess the neurocognitive profile of the patients with MS and then investigate how the deficits would impact their coping processes.

3.6 Summary of critique to previous research

To sum up, a few areas in the prior coping-related MS studies warranted further investigation after critical evaluation. Knowledge gaps were needed to address in the future research. First of all, it was in a strong sense that the majority of previous research did not adopt a theoretical framework to assess the interrelationship between stress, coping, and psychological adjustment in MS. Most of the findings were not theory-driven. Secondly, inspired by other chronic illness studies, acceptance of illness was also a significant coping resource especially for those patients with diseases characterized as unpredictable and incurable. Relatively more qualitative studies stressed that illness acceptance also had a potential role in helping the MS patients adapt to the illness well; however, its support from empirically view was scarce. It was highly recommended to look into this construct more empirically by quantitative data under the theoretical framework. Thirdly, cognitive impairments in patients with MS are common, but extremely limited previous research took this into consideration in coping. The extent to which various impaired cognitive domains affecting the patients' choices of coping strategies and perceptions of resources was poorly studied.

Taken together, the current study aimed to address the above knowledge gaps in order to extend the existing knowledge body of coping in MS especially for Chinese populations.

3.7 Hypotheses

Based on the findings of previous literature, the current study came up with the following hypotheses:

- 1) Better psychological adjustment (reflected by decreased depressive symptoms and greater life satisfaction) would be directly predicted by lower levels of disease severity, symptoms, relapses, and lower numbers of MS-related life stressful events.
- 2) The negative consequences of stressors on psychological health would be partly buffered by the coping processes. It was predicted that certain types of coping strategies and/ or greater perceived social support and illness acceptance would take the protective role in promoting better adjustment even in the face of stress among the MS patients.
- 3) Cognitive functioning of the MS patients was hypothesized to interfere with the coping processes. Specifically, it was hypothesized that greater impairments in neurocognition would decrease the use of problem-focused coping strategy and reduce the levels of perceived social support and illness acceptance. It was reasoned that patients with fewer cognitive resources would find more difficult to employ planful action to deal with the stressors as well as to perceive support from their social environment and accept the illness. In this sense, coping was hypothesized to act as a mediator between neurocognitive deficit and psychological adjustment.

Chapter 4 – METHOD

4.1 Research methodology

The current study was theory-driven research guided by the theoretical work of Lazarus and Folkman (1984). It strived to investigate the coping process of the MS Chinese individuals in-depth. It was a cross-sectional design embracing both qualitative and quantitative methods. In social research, there has been an increasing trend of combining these two research methods in one study over the past decade (Ausman, 2003). This blending approach is called “triangulation”. According to Denzin (1970), triangulation is inclusive of multiple observers, combination of data sources and methodologies. The idea underpinning use of triangulation of measurement in this study was to maximize our understanding of how the sufferers coped with MS in day-to-day life in a broader and deeper perspective by taking the unique benefits of both methods. Studying coping in research is not only confined to the coping process in which usually involves coping resources and strategies, but it may also pay attention to how MS brings destructive power to affect the daily functioning/ activities of these individuals which is more related to background. To the best of my knowledge, there is currently no empirical study focusing the topic of coping in MS in Chinese population. Being the first research on MS coping in Hong Kong, the current study aimed at examining this thoroughly, systematically, and meaningfully. In view of this purpose, this study not only put an emphasis on the coping process, but it also particularly documented the stressful situations caused by MS in daily life. More innovatively, this study incorporated the element of cognitive functioning into the coping process. Based on the unique needs of the current study, it was decided to fuse both qualitative and quantitative methodology for a thorough

and comprehensive investigation.

Qualitative method was composed of semi-structured interview exploring the actual experiences living with MS in terms of subjective distress of the Chinese individual. Given that human experiences are often bound to the contexts, interview rather than scale is considered to be more capable of capturing a full and true picture holistically. It indeed provided a more detailed, complete, and contextual portrayal about how the lives of Chinese MS individuals in Hong Kong were ruined by MS. It supported completeness in the current research in such a way that the precursor of coping – stressor was well-understood. Before the formal start of data collection, preliminary individual interviews with 15 patients with MS were conducted in the local hospitals. The patients freely expressed how MS induced stress in their lives through the discussion. Indeed, the data generated from the above preliminary interviews could facilitate the later quantitative part by acting as a precursor to the development of an instrument entitled “The Chinese MS Patient Stress Checklist”. This instrument would be further used in semi-structured interview during the formal data collection stage.

Quantitative method comprised a battery of neuropsychological tests and a series of standardized questionnaires tapping coping-related variables such as resources as well as strategies, and psychological well-being in terms of depressive symptoms and general life satisfaction. The need of getting quantified data was to testify and confirm the hypothesized theoretical framework. It could be helpful in explaining to what extent one set of variables was related to another. In order to appraise the influence of cognition on the coping process, it was essential to obtain the data in an objective way that domains of cognitive functioning had to be measured by objective and well-standardized neuropsychological assessment. It was inappropriate to rely on the participants’ self-reported on their cognitive performance

because their moods were found to interfere with their subjective complaints of cognitive functioning (Kinsinger, Lattie, & Mohr, 2010). The remaining study variables were assessed using valid and reliable questionnaires which have been locally validated.

To sum up, the current study adopted triangulation approach in assessing stress and coping as well as the role played by cognitive functioning in the coping process in the Chinese MS individuals. By using the combination of qualitative and quantitative methods could complement the inadequacies of each research method, making a stronger research design. These two methods are not mutually antagonistic. Neither the results coming from qualitative nor quantitative methods alone could yield the holistic outcomes of the two blended. The whole is greater than its part.

4.2 Participants

Seventy-two Chinese patients including 18 males and 54 females with a confirmed diagnosis of MS were recruited from the neurology clinics in the five local hospitals – Queen Elizabeth Hospital, Princess Margaret Hospital, United Christian Hospital, Pamela Youde Nethersole Eastern Hospital as well as Kwong Wah Hospital. 82 MS patients were approached when they attended their medical follow-up appointments. Among them, 10 patients did not enroll in the current study; 2 cases were unwilling to join, and 8 cases were excluded out from the exclusion criteria listed below. The refusal rate was 0.12.

Inclusion criteria of the participants were 1) a neurologist's confirmed diagnosis of MS on the basis of McDonald criteria (McDonald et al., 2001), which are now the newly revised diagnostic criteria for MS among international professionals; 2) age between 18 and 65; 3) Cantonese-speaking; 4) able to give informed consent.

Exclusion criteria were 1) dementia (below the cutoff score of 23 on the Mini-Mental

State Examination); 2) significant visual problems since poor vision would preclude the participants from doing the neuropsychological tests; 3) a history of central nervous system disorder other than MS (e.g. stroke, epilepsy), CNS opportunistic infection, psychotic disorders, head injury with loss of consciousness exceeding 30 minutes, significant developmental disorder, substance abuse or dependence in the past 3 months. .

4.3 Procedure

The current study had been approved by the Research Ethics Committee in Kowloon Central/ Kowloon East Cluster, Kowloon West Cluster, and Hong Kong East Cluster of the Hospital Authority in Hong Kong.

4.3.1 *Preparation*

Preliminary interviews

Prior to the start of formal data collection, 15 volunteers with MS (including both males and females) recruited in the neurology clinics were interviewed individually in relation to their experiences living with MS day-to-day life. All of them agreed to be audio-taped during the interviews. These interviews served two main purposes: firstly, facilitating the project-in-charge research student to get a deeper understanding of the Chinese patients with MS and to be more familiar with the nature, symptoms, and destructive power of MS; secondly, setting up the foundation to generate the items of subjective stressful situations elicited by MS for the use in a semi-structured interview in the formal data collection. The examples of questions used to probe the patients to freely, comfortably describe and talk about the disease in any aspects were as follows: (1) Could you please tell when and how you had been diagnosed to have MS? (2) What was wrong with your body at that time? (3) How

has MS been affecting your life; for example, how does it change your physical health? How does it bring any kinds of stressful situation in your life? Due to the sake of producing a checklist of MS-related stressful situations, the emphasis of interview was put on how MS had caused distress in the Chinese patients' lives. The interview last for approximately 45 minutes.

Thematic analysis

Thematic analysis was employed to analyze the data generated from the interviews. According to Braun and Clarke (2006), it is a common, reliable, and useful method of identifying, analyzing, and reporting patterns within data in qualitative research. Given its strengths, this method was believed to be suitable for the current study to extract any main themes of stressful situations caused by MS among the patients, making the checklist of subjective stressors for the use in formal data collection. The 15 audio-taped preliminary interviews were firstly transcribed verbatim by an independent research assistant with experience in qualitative research. The research student and this research assistant then independently read and re-read the transcripts several times to identify the main themes about MS-related stressors in daily lives. After that, they met to compare the results and also reached a consensus on the primary themes generated from the participants' real-life experiences. There were in total 10 main themes. The checklist of stressors among Chinese patients was presented in the "Measures" section.

Selection of the neuropsychological tests

A battery of neuropsychological tests had to be selected so as to look into the cognitive performance profile of Chinese patients with MS. It would be ideal if the chosen test was well-recognized as a validated tool for examination in MS and/ or if the test has gained its validity in the Chinese populations in Hong Kong. Moreover, it was prone to pick those tests which had normative data derived from Chinese

populations and were relatively less cultural bounded. Based on these criteria, the choices of the tests were driven by two sources – (1) Benedict et al.'s (2006) the Minimal Assessment of Cognitive Function in MS (MACFIMS) as well as (2) a local HIV study (Au, Chan, Taylor, & Li, 2010; Chan, 2011), in collaboration with the HIV Neurobehavioural Research Center from the University of California at San Diego in the United States, employing a variety of cognitive tests to assess the cognition of Chinese persons with HIV/ AIDS in Hong Kong. The HIV battery of neurocognitive tests has been translated into Chinese version by Heaton and his team in Mainland China; it has also partially validated in Hong Kong.

The current study targeted to examine the cognitive functioning of the MS patients in a comprehensive manner by which verbal memory, visual memory, executive functioning, attention and speed of information processing, psychomotor functioning, verbal fluency, and visuospatial ability would be evaluated. Taking the MACFIMS as a reference, four out of seven neuropsychological tests were selected which were the Brief Visuospatial Memory Test-Revised (Benedict, 1997), the Symbol Digit Modalities Test (Smith, 1982), the Paced Auditory Serial Addition Test (Diehr et al., 2003; Gronwall, 1977), and the Benton Judgement of Line Orientation Test (Benton, Varney, & Hamsher, 1978) as well. The remaining three were not chosen due to unavailability of Chinese norms in Hong Kong. Four additional cognitive tests from the local HIV study were included for assessment; they were the Wisconsin Card Sorting Test-64 Card Version (Kongs, Thompson, Iverson, & Heaton, 2000), the Trail Making Test - Part A (Army Individual Test Battery, 1944; Heaton, Grant, & Matthews, 1991), the Grooved Pegboard Hand Test (Heaton et al., 1991; Kløve, 1963), and also verbal fluency (Gladsjo et al., 1999; Piatt, Fields, Paolo, Koller, & Tröster, 1999). Since the stimuli for testing verbal memory were more culturally sensitive, a local developed and validated Chinese-word memory test was

preferred. Thus, the Hong Kong List Learning Test 2nd Edition (Chan, 2006) was used. It also had been employed in assessing HIV patients' verbal memory performance in the previous local study (Au et al., 2008). Briefly speaking, the current study contained in total nine cognitive tests in the battery. It was well-documented that all of these tests were sensitive to subcortical-related cognitive functioning changes (Au et al., 2010; Benedict, Cookfair et al., 2006; Chan, 2011).

Origin of normative data for reference and comparison

In order to establish the preliminary neurocognitive performance profile of the MS Chinese patients, it was necessary to compare their test mean scores with those scores achieved by the healthy control group in Hong Kong. In the current study, all of the normal control group data except from the Hong Kong List Learning Test-2nd edition, Symbol Digit Modalities Test, and Benton Judgement of Line Orientation Test were obtained from the HIV study (Au et al., 2010; Chan, 2011). In 2006, Chan published the normative data of the Hong Kong List Learning Test-2nd edition, and these data would be used for reference. Meanwhile, the norms of the Symbol Digit Modalities Test and Benton Judgement of Line Orientation were retrieved from Lee and Wang's (2009) large-scale work on building up the database of neuropsychological measures conducted in the Chinese sample in Hong Kong. The patients and controls were matched demographically in terms of age and education year.

4.3.2 Formal data collection procedures

Patients with MS were approached when they attended the regular medical appointment in the outpatient neurology clinics. Before inviting the patients to enrol in the research, the research student being responsible for this project would have a conversation with them in order to get a basic understanding of their disease history

and current disease status. The conversation was also helpful in screening the patients who were eligible to join the study according to the inclusion and exclusion criteria. The eligible patients would then further be fully explained the purposes and content of the current study and recruited as participants. They were given time to consider whether they would like to take part. Upon agreement, written informed consent was obtained from each participant. They were also informed the right to withdraw from the study at any time without affecting their medical service/ treatment received in the local hospital. After these procedures, the MMSE as a screening test would be firstly administered to screen out those with the score below 23. These participants would be dismissed and politely explained that they did not meet the inclusion criteria.

The current study was conducted in an individual approach. All of the assessments were completed face-to-face on the same day. Demographic information and clinical characteristics were obtained from either the participants themselves or the medical record. They had to accomplish a battery of neuropsychological assessment and semi-structured interviews about the topic of MS-induced distress in which the conversation would be audio-recorded upon the participants' permission. Also, they were told to fill in the remaining questionnaires regarding coping and psychological well-being (as listed in 4.4 Measures). The assessment and interviews were administered by the supervised, qualified research student with proper training provided by clinical psychologists. It would take about 2 hours to complete. In the end of the study, the participants would be given an opportunity to ask the researcher any questions related to this study.

4.4 Measures

The current study involved semi-structured interview in relation to stressors caused

by MS, a battery of objective neuropsychological tests, and self-reported measures tapping coping-related variables as well as psychological outcomes. The interrelationship of stress, coping resources – perceived social support and illness acceptance, and coping strategies with 1) depressive symptoms as well as 2) general life satisfaction were examined in details. In particular, the roles of specific cognitive functioning domains playing in the above associations were further explored.

4.4.1 Demographics and socioeconomic characteristics

Demographic information including age, gender, and education years was obtained from the participants. In terms of socioeconomic characteristics, occupation and monthly income were also collected.

4.4.2 Clinical characteristics

Disease-related information was obtained from the participants as well as their medical records. More specifically, clinical variables including diagnosis duration, symptom duration, number of recently perceived symptoms, and frequency of relapses were self-reported by the participants. Types of MS (e.g. RR/ PP/ SP) and the current score on the Expanded Disability Status Scale (EDSS; Kurtzke, 1983) were retrieved from the medical records written by the neurologists. The EDSS is the commonly used measure by the neurologists to indicate the disease severity of patients with MS. It ranges from 0 (normal neurological examination) to 10 (death due to MS) with an interval of 0.5. This scale provides an overall score reflecting functioning in seven areas: visual, sensory, brainstem, bowel and bladder, cerebella, ambulation, and pyramidal. According to Provinciali, Ceravolo, Bartolini, Logullo, and Danni (1999), the clinical classifications for the EDSS's cutoff scores are as follows: mild (0 – 3.0), moderate (3.5 – 6.0), and severe (> 6.5).

4.4.3 Stressors

Stressors which were the independent variables were classified into two groups – objective versus subjective. The objective stressors were related to disease-specific variables such as MS duration, relapse rate, illness severity, and number of recent symptoms. The subjective stressors emphasized more on how the individuals with MS experienced the stressful situations induced by the illness in their lives; therefore, semi-structured interviews were adopted to get a deeper understanding. In this part, the participants were given the Chinese MS Patient Stress Checklist (please refer to Table 1), which was generated from the preliminary interviews with the 15 MS patients in the pre-formal data collection phase, and were asked to endorse which stressful events had ever occurred to them. They would be also given an option to specify any other stressors which were not listed in the checklist. The number of stressful events was counted. Besides of filling in the checklist, the participants would be further interviewed to elaborate how MS brought difficulties to their lives by going through the endorsed stressful events bit by bit.

4.4.4 Neuropsychological assessment

Neuropsychological evaluation of cognitive functions was administered using a comprehensive battery of nine neuropsychological tests as follows: The Hong Kong List Learning Test 2nd Edition (HKLLT; Chan, 2006), the Brief Visuospatial Memory Test-Revised (BVRT-R; Benedict, 1997), the Wisconsin Card Sorting Test- 64 Card Version (WCST-64; Kongs et al., 2000), the Symbol Digit Modalities Test (SDMT; Smith, 1982), the Trail Making Test, Part A (TMT – Part A; Army Individual Test Battery, 1944; Heaton et al., 1991), the Paced Auditory Serial Addition Test (PASAT-3 sec; Diehr et al., 2003; Gronwall, 1977), the Grooved Pegboard dominant and non-dominant hand tests (Heaton et al., 1991; Kløve, 1963), verbal fluency in

terms of animal semantic fluency (Gladsjo et al., 1999) as well as action fluency (Piatt et al., 1999), and the Benton Judgement of Line Orientation Test Form H (JLO; Benton et al., 1978). The assessed cognitive domains covered verbal and visual memory, mental flexibility, attention and information processing speed, psychomotor functioning, verbal fluency, as well as visuospatial ability (shown in Table 2).

The Hong Kong List Learning Test 2nd Edition (HKLLT)

The HKLLT, which was a locally developed Chinese test, was used to assess verbal memory. It had two conditions – random condition (RC) and blocked condition (BC). In each condition, the participants were instructed to learn a list of sixteen 2-word Chinese nouns. There were three free-recall trials followed by 30-min delayed recall, and new/ old recognition trials. The number of the total score of delayed recall was the dependent variable.

The Brief Visuospatial Memory Test-Revised (BVMT-R)

In the BVMT-R, the participants were shown a matrix of six visual designs on an 8.5 x 11-inch sheet for 10 seconds. They had to recall the designs using paper and pencil without time limit. Based on the scoring criteria of accuracy and location, each design got a score of 0, 1, or 2. This test included three free-recall trials followed by 25-min delayed recall, and yes/ no recognition trials. The dependent measure for visual memory was the total score of delayed recall.

The Wisconsin Card Sorting Test- 64 Card Version (WCST-64)

The WCST-64 was employed to assess executive function. It was a computerized test. The participants were demonstrated with four cards in a row on the top of the screen. Each card had a particular design varying in different numbers (i.e. 1-4), colours (i.e. red, green, yellow, and blue), and shapes (i.e. circle, triangle, cross, and square). They had to accomplish 64 trials in matching the stimulus card to one of the four cards placed on the top in accordance with three different principles (i.e. number,

colour, and shape). The rules would not be told to them during the test. The dependent variable was the total correct response and perseverative errors.

The Symbol Digit Modalities Test (SDMT)

The SDMT presented a series of nine symbols to the participants, and each symbol was associated with a digit from 1 to 9 in a key at the top of A4-sized paper. A pseudo-randomized sequence of symbols was displayed in the remainder of the page. The participants were asked to fill in the digit paired with each symbol as quickly as possible within 90 seconds. The dependent measure was the number of correct responses.

The Trail Making Test, Part A (TMT – Part A)

There were 25 circles as stimuli in the TMT – Part A; each was assigned a number starting from 1 to 25. The participants were required to draw a straight line to connect the numbered circles in ascending order as soon as possible. The dependent variable was the completion time in seconds.

The Paced Auditory Serial Addition Test (PASAT-3 sec)

The PASAT-3 sec was an auditory test in which digits ranging from 1 to 9 were consecutively broadcast one by one with intervals of 3 seconds. The participants needed to compute and read aloud the summation of the digits tied up together, that is, the first digit and the second digit, the second digit and the following digit and so on. The number of correct responses was the dependent measure.

The Grooved Pegboard Hand Test

The participants were presented with a pegboard having 25 holes with randomly positioned slots. Meanwhile, there were pegs which had a round side and a square side. The participants were told to pick up and rotate a peg in order to insert into the hole on the board as fast as possible. They were only allowed to use one hand to do the task. There were two trails – one with dominant hand, another with non-dominant

hand. The total completion times measured in seconds for the two trial were the dependent variables.

Verbal fluency

For animal and action fluency, the participants were instructed to respectively say the names of animals and verbs as many as possible without repetition within one minute. The dependent measures were the number of correct responses in each trial.

The Benton Judgement of Line Orientation Test Form H (JLO – Form H)

In the current study, Form H of the JLO was used to test the visuospatial ability of the participants. It required the participants to identify the angle between two stimulus lines among a set of 11 visual array lines covering 180 degrees. It contained 30 items. Either pointing or oral responses were permitted. The dependent variable was the total correct responses.

4.4.5 Coping resources

4.4.5.1 Social support

The social provisions scale (SPS; Cutrona & Russell, 1987; Russell & Cutrona, 1984) was utilized to measure perceived social support of the participants in their social relationships. The participants were requested to self-report 24 items on a 4-point scale, with response ranging from 1 (strongly disagree) to 4 (strongly agree). A mixed of positively and negatively worded sentences were found in this instrument. Examples of the positive items are as follows: “There are people I can depend on to help me if I really need it” and “There is someone I could talk to about important decisions in my life”. Examples of the items with negative tone include “I feel a lack of intimacy with another person” and “No one needs me to care for them”. After reversal of the negative items, the total score could be calculated by summing all items. The total score ranges from 24 (lowest perceived social support) to 96 (highest

perceived social support). Its validity to use locally has been provided for evidence (Chan, 2006). The Cronbach's α coefficient of this instrument was 0.94 in the sample.

4.4.5.2 Acceptance of illness

The acceptance of chronic health conditions scale (ACHC Scale; Stuifbergen et al., 2008) was employed to appraise the illness acceptance. According to the scale's authors, illness acceptance has been conceptualized as a belief held by the participants towards the illness. The ACHC Scale is a 10-item Likert scale asking the participants to indicate their degree of agreement (ranging from 1 = strongly agree to 5 = strongly disagree) with each statement. Among the 10 statements, 4 of them are with positive worded attitude (e.g. I think of MS as just part of who I am), and 6 of them are negative worded (e.g. I think of MS as a curse). Reversed scoring was required for the positive items. The total score of the 10 items ranging from 10 to 50 reflected the extent to which the respondents accepted MS. Higher total score represented higher degree of acceptance. The validity and reliability of this scale were already proved in the samples of persons with MS in the past (Stuifbergen et al., 2008). In this sample, the Cronbach's α coefficient of this scale was 0.69.

4.4.6 Coping strategies

The Chinese Way of Coping Questionnaire (CWOC; Chan, 1998) was used to investigate the methods by which the participants used to combat against stress in lives. It was composed of four subscales – (1) Active problem solving; (2) Distancing; (3) Seeking social support; (4) Wishful thinking. Each subscale contains four items; there are in total 16 items. The participants were instructed to rate the usage frequency of each method using Likert scale with a response of 4 options ranging

from 0 (not applicable/ never) to 3 (always). Each subscale would be obtained a total score by summing its respective four items. The Cronbach's α coefficients of the four subscales were 0.81, 0.58, 0.83, and 0.64 respectively in the sample.

4.4.7 Psychological health outcomes

Psychological health outcome measures were evaluated in two aspects – affective well-being like depression and a global sense of well-being reflected by life satisfaction.

4.4.7.1 Depression

The Chinese version of Beck Depression Inventory-II (BDI-II; Beck, Steer, & Brown, 1996) was administered as a self-reported instrument to evaluate depression of the participants in the past two weeks. It contains 21 items; each item represents a symptom of depression as listed in the *Diagnostic and Statistical Manual of Mental Disorders* Fourth Edition (DSM-IV; American Psychiatric Association, 2000) such as sadness, self-dislike, and loss of interest. Within each item, there are at least four choices arranged in increasing intensity of one particular depressive symptom; for example, 0: I do not feel sad; to 3: I am so sad that I cannot stand it. The score of each item ranges from 0 to 3 and is summed to present a single total score. The total score was classified into four severity of depression – 0-13 indicates minimal symptoms; 14-19 represents mild depression; 20-28 shows moderate level; and 29-63 demonstrates severe depression (Beck et al., 1996). It has been supported for valid use locally (Byrne, Stewart, & Lee, 2004), and its Cronbach's α coefficient was 0.90 in the sample.

4.4.7.2 General life satisfaction

The Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985)

containing six items was used to survey the current global life satisfaction of the participants, representing subjective well-being. It has been validated locally (Au et al., 2009; Shek, 2002). The items are global but not specific in nature. The first five items depict positive feelings; for example, “I am satisfied with the current life”. A 7-point scale ranging from 1 (strongly disagree) to 7 (strongly agree) is used to rate the respondent’s satisfaction. The sixth item asks how the respondent is satisfied with his/ her general life so far. The score ranges from 1 (very poor) to 7 (pleasant). The higher total score means more satisfaction in life. The Cronbach’s α coefficient of this scale was 0.90 in the sample.

4.5 Statistical analysis

As the current study adopted mixed research methods, analyses were performed by two approaches – qualitative and quantitative. The statistical software for quantitative data analyses included Statistical Package for Social Sciences for Windows Version 16 (SPSS, 2009) as well as EQS for Windows Version 6.1 (EQS; Bentler & Wu, 2003).

To begin with, the information obtained from the semi-structured interview of each participant was processed using thematic analysis. Each audio-taped interview was transcribed verbatim by the independent research assistant. She and the research student read the transcripts for a few times to identify any new main theme of stressor which was not mentioned in the Chinese MS Patient Stress Checklist. At the same time, they also looked into the chief reasons about how MS resulted in difficulties in their lives under each main theme. The results were reported on the basis on consensus between them. Lastly, the percentage of participants endorsing each subjective stressor was also computed.

In the field of quantitative analyses, several statistical methods were involved.

Descriptive statistics were computed to summarize the demographic and clinical characteristics of the sample and the outcome measures. To build up the cognitive functioning profile of MS patients, a series of *t*-tests were performed to compare the mean differences in the neurocognitive test measures between the MS group and healthy control group. Effect sizes were also calculated.

Neurocognition – Coping Strategy relationship

Besides of focusing on outcomes of psychological health, the current study would also explore the extent to which cognitive functioning predicted coping strategy utilized by the MS patients. Simple bivariate correlations were employed to gauge the relationship of cognitive test measures with the four types of coping methods – active problem solving, distancing, seeking social support, and wishful thinking. After all, the significant correlates would be entered in the stepwise regressions for each coping strategy for identification of predictors.

Relationships of Neurocognition, Stress, Coping with Psychological well-being

Concerning the coping-related areas, bivariate correlation was firstly performed to examine the degree of relationships between the study variables which included demographics, cognitive functioning, both objective and subjective stressors, coping resources – illness acceptance and social support, as well as coping strategies, and (1) depressive symptoms and (2) life satisfaction as dependent variables. Only those independent variables having significant correlations with the dependent variables were further entered into the next step of analysis.

Inferential analyses were adopted to look into how well the study variables had predicted psychological well-being of the patients with MS by employing hierarchical multiple regression or structural equation modeling. In accordance with Lazarus and Folkman's (1984) theoretical work, coping resources – social support and illness acceptance as well as coping strategies were particularly of interest to be

investigated their roles in reducing negative psychological outcomes. Thus, hierarchical multiple regression was used to examine the additional, incremental variances of these resources and strategies in accounting for psychological health even in the face of stressors in the Chinese patients. The hierarchical regression was conducted on each significant coping-related variable individually (e.g. social support and illness acceptance), and separate equation would be set up for the two dependent variables. Other than that, path analysis was administered to demonstrate the mediation roles of significant coping-related variables in the stress and psychological well-being relationship. More importantly, the unique contribution of cognitive functioning to the traditional stress-coping theoretical framework could be also studied in the path analysis. Because of the large number of analyses performed, the statistical significance level was adjusted to 0.01 (i.e. $p \leq 0.01$) in general, unless specified.

Chapter 5 – RESULTS

5.1 Descriptive analyses

In the sample ($n = 72$), 75% were females. The participants had a mean age of 37.19 in years ($SD = 9.99$), and they averaged 11.88 years of education ($SD = 2.75$). Their monthly income had a large discrepancy ranging from HKD 0 to 50000 ($M = 8286.89$, $SD = 10481.97$). Among all of them, 45.8% ($n = 33$) were still able to work, whereas 36.1% ($n = 26$) were unemployed due to MS. There were also 13.9% ($n = 10$) participants being housewife and 4.2% ($n = 3$) participants being students. The mean duration of symptoms and diagnosis in months were 97.38 ($SD = 75.55$) and 69.89 ($n = 55.20$) respectively. The majority of them belonged to relapsing-remitting MS ($n = 67$; 93.0%); the remaining had a form of progressive types – primary progressive ($n = 1$; 1.4%) and secondary progressive ($n = 4$; 5.6%). Their mean EDSS score was 2.39 ($SD = 2.36$) indicating mild disability in one functional system or minimal disability in two functional systems in this representative sample. Other clinical characteristics including number of recent symptoms and frequency of relapses were averaged 2.47 ($SD = 1.90$) and 4.01 ($SD = 4.45$) respectively. The global cognitive functioning of the participants was assessed with the MMSE of which the mean score was 27.94 ($SD = 1.53$). It showed that this representative sample's cognitive functioning was largely intact. The outcome measures of the neuropsychological tests, stress and coping-related variables, as well as psychological well-being in mean and standard deviation were presented in Table 3.

5.2 Neuropsychological functioning profiles of Chinese patients with MS in Hong Kong

In terms of cognitive domains, MS effects were found in both verbal and visual memory, executive functioning, attention and information processing speed, psychomotor functioning, verbal fluency, and visuospatial ability as well. The performance on the battery of cognitive tests of the Chinese patients with MS was compared to the local norm. There were no significant differences in age and education years between the MS and healthy control group ($p > 0.05$). A series of *t*-tests were employed to examine any differences in the mean scores on the test measures obtained by the MS patients and those derived from the norm. The Bonferroni correction for multiple comparisons was applied to reduce Type I error (i.e. statistical significance level was set at $p < 0.004$). The results were shown in Table 4. The patients performed significantly more poorly on all of the cognitive tests than did the control group. According to Cohen's (1992) criteria, effect sizes between 0.4-0.6 were considered to be medium, and effect sizes with values > 0.7 were large. It revealed that the effect sizes of the tests between two groups ranged from medium to very large. The largest effect size was found in BVMT-R delayed recall; in the opposite, the effect size of JLO was the smallest. The most affected domains were visual memory, followed by psychomotor functioning, attention and processing speed, verbal memory, executive functioning, verbal fluency, and finally visuospatial ability. In addition, the standard deviations of test measures in the MS group were larger than those in the control group. The spread of scores on TMT-part A and Grooved pegboard were noticeable to be 5 to 6 times wider in the MS group. Plus, the standard deviations of score the tests tapping verbal and visual memory and executive functioning were approximately larger by 2 times. It implied that there was

indeed a wider range of variability in cognitive ability among the MS patients.

Besides of the above statistical tests, z-scores based on the local norm were also computed to decide the percentage of MS patients in this sample having cognitive impairments. Following the suggestion made by Benedict et al. (2006), impairment was defined as a cut-off z-score < -1.5 for each individual cognitive test. Patient was said to suffer from neuropsychological impairment when s/he had the z-scores on two or more test measures < -1.5 . The frequencies of individual impaired test measures in the MS patients were illustrated in figure 2. The greatest percentage in deficit was 59.7% (TMT-part A), followed by 57.4% (Grooved pegboard non-dominant hand), 56.9% (BVMT-R delayed recall), 54.9% (Benton JLO), 48.5% (Grooved pegboard dominant hand), 45.1% (PASAT – 3 sec), 40.3% (verbal fluency – action), 38.6% (HKLLT BC delayed recall), 37.5% (SDMT), 36.1% (WCST-64 perseverative errors), 33.3% (HKLLT RC delayed recall), 30.6% (WCST-64 total correct), and the least was 20.8% (verbal fluency – animal). In accordance with the standard of deficits in two or more tests, 86.1 % of the MS patients in this sample were reported to be cognitively impaired.

5.3 Qualitative analyses – Subjective stressors caused by MS

Semi-structured interview focusing on stressors caused by MS was administered to each participant. Through the interviews, the details about the extent to which the patients' lives were deteriorated by MS were explored. As noted, the interview was on the basis of the Chinese MS Patient Stress Checklist, the following results endeavoured to integrally elaborate the actual difficulties encountered by the patients in daily lives. The stressors were reported in the order from the most to least frequently rated items by the participants.

1) Unpredictability of illness trajectory (90%)

90% of the participants agreed that the unpredictable nature of the disease was indeed a significant stressor. MS was just like a bomb. It could be attributed to the uncertainty about relapse rate and duration – when it would happen, where demyelination would occur, which neurological symptoms would have, and how long the worsening condition would last for. Most of the participants reported that they were living in the fear of this disease. They did not realize whether their bodies would return to the previous functioning status after relapse. They felt like life was not seized by them but by MS. They did not dare to make any long-term plans in their lives even only a plan for travelling. Uncertainty about MS made them feel everything in life was out of control.

2) Economic problems (81.4%)

A majority of the patients found themselves to be burdened with economic problems due to several reasons. First of all, some patients suffering from more severe symptoms (e.g. inability to walk properly and blurred vision) lost working capacity and became unemployed, leading to unstable or even nil monthly salary income. They could only rely on their families or the limited subsidization from the government for general expenses. Furthermore, parts of the patients also had to spend a certain amount of money on medication regularly; for example, interferon which was an injection to reduce the relapse rate and Chinese herbal remedy for the incurable symptoms. Even for those patients with stable monthly salary income, the treatment expenses had already consumed a part of their incomes, resulting in poorer quality of life by cutting down other luxuries or activities which they used to do.

3) Poorer work performance (80%)

Inability to mobilize as quickly as usual, increasing memory problems, as well as

becoming fatigue easily were the factors which caused the patients to perform work duties less efficiently when compared to the past. Some participants reported that they only had limited energies to deal with heavy workload of the jobs, resulting in slower work performance. A few participants who were students also complained that their learning ability had been declining since the occurrence of MS. Memory problems hindered the participants from remembering what to do in work or study. They needed extra effort in remembrance, resulting in additional mental tiredness after work.

4) Worry about own future (74.3%)

All patients indicating this as a stressor also worried about the physical conditions in future. Again, it was attributed to the unpredictable characteristics of MS. Relapse was a nightmare to them; nevertheless, they had no ways to guarantee it would not come. Poor physical condition would also elicit economic difficulties to them as they might not be capable of working to earn money. In addition, injecting Interferon endlessly was another problem. It definitely consumed those patients' savings constantly. Overall, physical health and economic status in future were the two main areas about which the patients were concerned a lot.

5) Worry about family's future (58.6%)

Patients had differential roles in the nuclear family, while one could be either other's spouse, parent, child or both of them. No matter what roles they bore in the family, they were also worried about the competence in taking care of the family instrumentally and emotionally in the future. They were frightened that they might not be able to bear responsibilities to provide sufficient love and support to the spouse, to bring up their own children and/ or to provide and care for their elder parents. Given that their condition might be deteriorated by the

illness, they regarded themselves as a heavy burden both in terms of physically, financially, and emotionally to the family in a very near future.

6) Fear of job loss (48.6%)

The patients were particularly afraid of losing jobs when MS relapsed. It was because the trajectory of MS was unpredictable that they were not sure whether their physical condition could go back to the previous neurological state so as to sustain to work again. Some of the patients wanted to continue working as they needed money for all kinds of expenses including medication, whereas some of them insisted on working as they deemed that working was a means to prove their values in the society. Besides of the fear produced in the relapse phase, some of the patients constantly dreaded being laid off by their employers since they had to get sick leave to see the doctor regularly especially for those who was now being prescribed injections to control the relapse rate.

7) Impact on social life (47.1%)

Patient's social life was interrupted as a result of a range of physical symptoms. Inability to walk properly, fatigue, bladder dysfunction, and blurred vision were the factors which made the patients significantly reduce their participation in outdoor activities such as family and/ or friend gatherings and those requiring energies (e.g. sports). Or else, they would selectively choose to go to some places where they were familiar with, so that they knew how long they had to walk and where the restroom was. Under some circumstances, in order to attend a gathering, the patients had to save energies a few days ago. In the worst case, some of the patients were forced to give up hobbies including sports, driving, and photography, affecting the quality of life of the patients.

8) Reproduction difficulties (42.9%)

A few patients mentioned that there was reduction in sexual interest since having

MS, resulting in less sexual activities. More importantly, most patients regardless of males or females were concerned about inheritance of the illness to their offsprings. As most of the married patients who endorsed reproduction as a stressor were at the age of golden period (20s – 30s), they indeed struggled much to decide if they should have a baby. They understood how painful it was to have MS, they purely did not want their offsprings to have a chance to suffer under the same circumstance as theirs.

9) Disclosure of disease to others (28.6%)

Some of the patients felt distressed by letting others especially employers as well as unfamiliar friends to know that they were diagnosed to have MS. Nowadays, awareness and information of MS is extremely scarce among people in Hong Kong. Thus, the physical conditions of the patients were usually misinterpreted as “all or none” by others. Whereas some laymen might exaggerate the patient’s condition as if it would have only gone from bad to worse, some might underestimate the unobservable but terrible MS-related symptoms (e.g. double vision, pain, loss of sensation, and swallowing difficulties) from which the patients suffered. A part of patients did mind how others would think of them. They did not will to disclose illness to their employers since they were afraid of being laid off due to employer’s lack of understanding about MS. For those who did not want their friends to know because they were fed up with repeatedly explaining to others what MS was and how it would devastate their lives.

10) Others (24.3%)

Loss of self-confidence – this stressor was mentioned by young patients who needed to walk with aid. They were bothered how people would think of them that why such as a young-looking lady would walk like that. Gradually, they lose confidence in themselves.

Finding partners – this distress was mainly reported by the patients at the age of 20s. They were uncertain about the chance to find true love because they thought that no one would love to spend the whole life with someone with the chronic debilitating disease.

Difficulties in pursuit of dream job – a few young patients have just been beginning to build up their career; however, they struggled to choose in between pursuit of a dream job which might elicit high level of stress and doing a job with much less stress. The sake of this kind of struggle rooted from the fact that stress might be more likely to increase the relapse rate. This group of young patients was in a tough situation where they should sacrifice ambition for health.

11) Concerned about foetus's health (4.3%)

Female participants were particularly worried about the foetus's health when they were pregnant. They were fear of relapse during pregnancy that they did not ensure what profound effects might have on the foetus. Neither could the professionals provide accurate information on this aspect.

Conclusion

The disasters brought by MS spread out a variety of areas in life of the MS patients. Uncertainty and unfavourable neurological symptoms were the two main murderers to ruin the patients' lives. Living in the face of MS unpredictable development, the patients were very much concerned about their working ability because losing job could lead to heavy financial burden on them. Uncertainty also gave them extra worries about the future; for example, how their and their family's lives would be, the health of their offsprings, and the possibility to find true love. Other than that, the occurrence of symptoms such as inability to mobilize properly, fatigue, and bladder dysfunction destroyed the patients' quality of life ranging from mildly to severely. Due to the symptoms, some of the

patients were no longer to be employed. Even personal life was significantly negatively influenced by giving up hobbies (e.g. photography) and/ or absence the gatherings with family or friends. For some of the patients whose disease was at more advanced stage, MS indeed completely changed their lives adversely which they could have never anticipated. MS not only caused physical damage to the sufferers, but it also induced a huge amount of psychological distress to them.

5.4 Quantitative analyses relating to the coping process and outcome

5.4.1. The relationships between study variables and psychological outcomes

Prior to testing the hypotheses and models, simple bivariate correlations were used to assess the extent of relationships between the study variables and psychological well-being as outcome variables. The study variables comprised demographics (age, education years, & income), objective stressors (illness parameters – duration of symptoms and diagnosis, EDSS, number of recent symptoms, & frequency of relapses), number of subjective stressors induced by MS, neuropsychological performance (MMSE, HKLLT RC 30-min delayed recall, HKLLT BC 30-min delayed recall, BVMT-R 25-min delayed recall, SDMT, WCST-64 – total correct and perseverative errors, TMT – Part A, Grooved Pegboard dominant and non-dominant hand, verbal fluency in animal and verb, PASAT-3 sec, & Benton JLO), illness acceptance and social support as coping resources, and coping strategies as well. Among all of the independent variables, only education years, number of recent symptoms, number of subjective stressors, HKLLT BC 30-min delayed recall, SDMT, illness acceptance, and social support were considerably correlated with depressive

symptoms ($p \leq 0.01$). It revealed that better education, cognitive performance, acceptance, and social support were correlated with lesser depressive symptoms, whereas more number of recent symptoms and subjective MS-related stressors were associated with higher level of depression. In terms of general life satisfaction, EDSS, subjective stressors, HKLLT BC 30-min delayed recall, SDMT, illness acceptance and social support were the significant correlates ($p \leq 0.01$). Similarly, higher level of cognition, acceptance, and social support were related to better sense of life satisfaction. In contrast, higher score on EDSS indicating more severe neurological impairment and greater number of subjective distress led to lower satisfaction in life. As noted, none of the coping strategies were comparably associated with psychological health in this MS sample. Table 5 depicted the significant Pearson's correlation coefficients (r) of these variables.

5.4.2. Exploring the roles of cognitive functioning in coping strategies

As mentioned in the outcomes of bivariate correlation with psychological health among the focal study variables, coping strategies were not the significant correlates. Nevertheless, certain cognitive test measures were found to be considerably associated with the coping strategies. In order to reduce the type I error, Bonferroni adjustment on the alpha level was applied in the following correlational analyses. Intercorrelations among 13 cognitive measures and each coping strategy were conducted. Thus, the significance level was set at 0.004 (i.e. $13/0.05$).

Active problem solving – SDMT ($r = 0.43, p \leq 0.001$), WCST-64 - total correct ($r = 0.35, p = 0.004$), WCST-64 - perseverative errors ($r = -0.41, p \leq 0.001$), animal verbal fluency ($r = 0.39, p \leq 0.001$), and PASAT-3 sec ($r = 0.46, p \leq 0.001$) were found to be significantly related to the coping strategy of active problem solving.

Those participants who had better functioning on the cognitive domains of information processing speed, executive functioning, and verbal fluency were prone to use more active problem solving when they encountered difficulties.

Distancing – The significant correlates included HKLLT RC ($r = -0.51, p \leq 0.001$) and BC ($r = -0.55, p \leq 0.001$) 30-min delayed recall, BVMT-R 25-min delayed recall ($r = -0.46, p \leq 0.001$), SDMT ($r = -0.44, p \leq 0.001$), TMT-Part A ($r = 0.41, p \leq 0.001$), as well as animal verbal fluency ($r = -0.47, p \leq 0.001$). Participants who adopted distancing as a way to deal with distress were more likely to have poorer verbal and visual memory, slower speed in information processing, and lower level of verbal fluency.

Seeking social support – only HKLLT BC 30-min delayed recall ($r = 0.46, p \leq 0.001$) had significant association with this coping strategy. Participants with better verbal memory would be more likely to seek others' help when facing problems.

Wishful thinking – no cognitive measures were reported to be correlated with it. It seemed that the choice of wishful thinking as coping strategy was independent of cognition.

In order to identify the relative contribution of each cognitive measure to the prediction of coping strategies, three stepwise multiple regressions were performed, one for each coping strategy except wishful thinking. The statistical outcomes were presented in Table 6. Regarding active problem solving, PASAT-3 sec ($B = 0.07, p < 0.05$) and WCST-64 perseverative error ($B = -0.08, p < 0.05$) were the two significant predictors in the full model ($F [2, 70] = 8.03, p < 0.01$). They totally explained 23% of the variance in problem solving, with each contributed to 6% of unique variance. The size and direction of the regression coefficients suggested that more frequent use of active problem solving in coping was accompanied by better speed of information processing and executive functioning. They had similar predictive ability as indicated

by the same value of unique squared semipartial correlation. When looked into distancing, it was confirmed that just verbal memory was a significant predictor in accounting for 39% of the variability of the use of distancing in coping. The full model ($F [2, 70] = 19.04, p < 0.01$) contained two memory measures which were HKLLT BC ($B = -0.18, p < 0.01$) and RC ($B = -0.20, p < 0.05$) 30-min delayed recall. Delayed recall in blocked condition and random condition respectively made 7% and 6% contribution to the variance in distancing. They together provided 22% of shared variability. Patients with better memory tended to use less coping method involving distancing. Likewise, verbal memory was a useful correlate in predicting seeking social support. The full model was significant ($F [1, 70] = 17.01, p < 0.01$), and it only included HKLLT BC 30-min delayed recall ($B = 0.29, p < 0.01$). Verbal delayed recall in blocked condition considerably contributed 21% of variance in this coping strategy. Coping with stress by seeking support from others was featured with higher functioning in memory.

5.4.3. Investigating the direct effects of social support on psychological health

Hierarchical multiple regressions were performed to determine the buffering effects of social support on psychological well-being as proposed by Lazarus and Folkman's theoretical model (1984). It was suggested that perceived social support considered to be one of the coping resources could cushion the burden of stress on psychological health. As a result, hierarchical regressions were implemented to investigate the additional variance in depressive symptoms and life satisfaction could be explained by social support itself when controlling for demographics, cognition, and stressors which had significant relations with the dependent variables. Depressive symptoms and life satisfaction were analyzed using separate hierarchical regressions.

The transactional model of stress and coping dictated the entry sequence of a set of predictors into the regression equation. Demographics and cognitive functioning seen as the pre-existing characteristics of the participants were entered into the first block. Both objective and subjective stressors were entered at the second step after the covariates. Social support was then entered into the third block.

The results of the hierarchical regression analyses on depressive symptoms were summarized in Table 7. Three models were established to determine the predictive power of each significant correlate on BDI-II. In model 1, education years and cognitive functioning (HKLLT BC 30-min delayed recall & SDMT) accounted for 17% of variance in BDI-II ($F [3, 69] = 4.52, p < 0.01$). In model 2 in which stressors were added, the model was significantly improved ($\Delta F = 5.82, p < 0.01$). Number of recent symptoms and that of subjective MS-related stressors in daily life additionally explained 13% of the variance in BDI-II. Social support was included in model 3; similarly, the model was further significantly improved ($\Delta F = 13.88, p < 0.001$). Social support contributed 13% unique variance to the prediction of BDI-II. The R^2 of 0.43 indicated that nearly one half of the variability of depressive symptoms could be predicted by education years, cognition, number of recent symptoms, number of subjective stressors, and together with social support. Social support contributed the most unique variance (13%) followed by number of subjective stressor (7%), cognition (3%), number of recent symptoms (1%), and education years (less than 1%). The six independent variables in combination accounted for another 18% in shared variability of BDI-II. Among these predictors, only social support ($t = -3.73, p < 0.001$) and number of subjective stressor ($t = 2.97, p < 0.01$) provided significant unique contribution. It was suggested that more depressive symptoms in the patients with MS were made with poorer perceived social support and a larger number of stressful situations induced by the illness in daily life. Among these two, social

support was much more important, as demonstrated by the unique squared semipartial correlation.

Table 8 demonstrated the hierarchical regression results on general life satisfaction. As shown in the bivariate correlation table (Table 4), no demographics had significant association with life satisfaction; therefore, only cognition in terms of HKLLT BC 30-min delayed recall and SDMT was assessed in model 1. Cognition could predict 9% of variance in SWLS. EDSS, which indicated the MS severity and was considered as an objective stressor, and number of subjective stressors were added in the model 2. They succeeded in contributing 12% of additional variability of general life satisfaction ($\Delta F = 4.98, p \leq 0.01$). In model 3, social support was further entered; however, it did not improve the overall model ($\Delta F = 4.64, p = 0.04$). In this sense, social support was not significantly predictive of life satisfaction in the Chinese patients with MS. Model 2 would be adopted as the final model ($F [4, 69] = 4.27, p < 0.01$). The R^2 of 0.21 demonstrated that one fifth of the variability of general life satisfaction could be estimated by cognition, disease severity, and subjective stressors. Subjective stressor contributed the most unique variance (8%), followed by EDSS (3%), HKLLT BC 30-min delayed recall (1%), and SDMT (1%). These four predictors in combination explained another 8% in shared variability of SWLS. Subjective stressor was the only predictor which had unique contribution ($t = -2.49, p \leq 0.01$). It was argued that lower sense of general life satisfaction was come with greater stress elicited by MS in life.

5.4.4. Investigating the direct effects of illness acceptance on psychological health

Based on the theoretical framework, acceptance of illness was also hypothesized to alleviate the negative impact brought by stress on psychological well-being of the

MS patients. Similar to the procedures applied in assessing social support in the hierarchical regression, the unique, additional predictive power of illness acceptance were estimated after controlling for the variances in depressive symptoms and general life satisfaction contributed by demographics, cognition, and stressors.

The results relating to the prediction of depressive symptoms were depicted in Table 9. Three models were set up to find out the predictive power of each significant correlate on BDI-II. Again, in model 1, education years and cognitive functioning (HKLLT BC 30-min delayed recall & SDMT) accounted for 17% of variance in BDI-II ($F(3, 69) = 4.52, p < 0.01$). In model 2 in which stressors were added, the model was significantly improved ($\Delta F = 5.82, p < 0.01$). 13% of the variance in BDI-II was additionally accounted for by the number of recent symptoms and that of subjective MS-related stressors in daily life. Acceptance of illness was entered into the model 3 which also showed significant improvement ($\Delta F = 7.68, p < 0.01$). Acceptance uniquely contributed 11% variance to the prediction of BDI-II. Cognition, stressors, as well as illness acceptance totally explained 37% of variability of depressive symptoms. Acceptance contributed the most unique variance (11%), followed by education years (3%), number of symptoms and that of subjective stressors (2% each), SDMT (1%), and HKLLT BC 30-min delayed recall (less than 1%). Moreover, only acceptance of illness was found to be the useful predictor contributing significant unique variance ($t = -2.77, p < 0.01$), suggesting that increased acceptance of MS could reduce depressive symptoms.

Table 10 demonstrated the hierarchical regression results on general life satisfaction. Likewise, cognition could predict 9% of variance in SWLS in the model 1. EDSS and number of subjective stressors were put into the model 2. They succeeded in contributing 12% of additional variability of general life satisfaction ($\Delta F = 4.98, p \leq 0.01$). Acceptance of illness was involved in the model 3 in which

significant improvement was observed ($\Delta F = 7.24, p < 0.01$). The main effect of acceptance was identified, and it was successfully to increase the unique variance of 8% in SWLS. The R^2 of 0.29 informed us that approximately one third of the variability of general life satisfaction could be predicted by cognition, disease severity, subjective stressors, and illness acceptance as well. Acceptance contributed the most unique variance (8%), followed by EDSS (3%), subjective stressor (2%), and both HKLLT BC 30-min delayed recall and SDMT (less than 1%). These five predictors in combination explained another 16% in shared variability of SWLS. In this case, acceptance of illness was the only predictor which had unique contribution ($t = 2.69, p \leq 0.01$). It was regarded that better general life satisfaction was made with elevated degree of acceptance of MS.

5.4.5. Examining the significance of memory in the mediation effects of coping resources on psychological health

Path analysis was used to evaluate the contribution of a particular domain of cognitive functioning – verbal memory to the coping process dictated by the traditional stress-coping transactional model (Lazarus & Folkman, 1984). Among all cognitive domains, verbal memory was selected based on its significant correlations with the two coping resources and psychological outcomes (dependent variables).

The hypothesized model mainly building on the transactional model of stress and coping had two routes. The first route followed the traditional perspective that coping resources could alleviate the devastating influence of stress on psychological health. Thus, the mediating roles of illness acceptance and social support in predicting depressive symptoms and general life satisfaction were particularly analyzed. The second route was one of the main contributions of the current study to incorporate verbal memory into the theoretical framework of stress and coping to

examine how the coping resource-psychological health relationship would be influenced by it. Only HKLLT-BC 30-min delayed recall (verbal memory) was included for analysis among the cognitive measures due to its significant correlations with the two coping resources and dependent variables. The intercorrelations of HKLLT-BC 30-min delayed recall (verbal memory), number of subjective stressors elicited by MS, illness acceptance, perceived social support, BDI-II and SWLS were depicted in Table 11.

Mediators were identified by the intercorrelation results. According to Baron and Kenny (1986), mediator has to be significantly associated with the independent and dependent variables, and when it is present in the model, there is a reduction in the relationship size between the predictor and outcome. In this sense, only acceptance of illness would mediate the relationship between subjective stressor and psychological health outcomes; both illness acceptance and perceived social support were expected to mediate the association of verbal memory with psychology adjustment. The model was elucidated in figure 3.

The full mediation model (Model 1; Figure 3) was tested by using path analysis. The results showed that the fit indices of model 1 were acceptable ($\chi^2 [8] = 15.35, p = 0.05, NNFI = 0.87, CFI = 0.93; GFI = 0.92, RMSEA = 0.13$). Yet, the Lagrange Multiplier test further suggested addition of a direct path from subjective stressor to BDI-II. As a result, the modified path model (Model 2; Figure 4) was established and further examined. Model 2 was supported by its satisfactory fit indices ($\chi^2 [7] = 11.07, p = 0.14, NNFI = 0.92, CFI = 0.96; GFI = 0.94, RMSEA = 0.09$). The fit indices of model 2 had been improved from model 1. Thus, model 2 would be more preferable to be the final model which indicated that acceptance of illness merely partially mediated the relationship between subjective stressor and depressive symptoms. The standardized coefficients of each pathway were shown in figure 4.

As portrayed in model 2, subjective stressor had a direct impact on BDI-II and also indirect impact through illness acceptance on BDI-II and SWLS. Meanwhile, the effects of verbal memory on BDI-II and SWLS were fully mediated by acceptance and social support. The levels of illness acceptance and perceived social support were enhanced by better verbal memory, promoting better psychological adjustment. To sum up, verbal memory has been successfully confirmed its significant and unique role in affecting the coping process and psychological well-being in MS.

Chapter 6 – DISCUSSION

6.1 Cognitive impairments

One of the primary goals of the current study involved magnitude quantification of impairments in different cognitive domains in the Chinese MS patients compared with healthy controls. In this sample, the patients showed impairments ranging from medium to large effect sizes in all tested cognitive domains, although their global cognition remained intact which was reflected by the normal MMSE score. The effects differed across the domains with largest effects found in visual memory, followed by psychomotor functioning, attention and processing speed, verbal memory, executive functioning, verbal fluency, and finally visuospatial ability. These results were consistent with a recent meta-analytical work (Prakash et al., 2008) which showed that motor functioning, memory, and attention/ processing speed were the three largest detriments in cognition observed in the MS populations. The BVMT-R, Grooved pegboard, TMT-Part A, SDMT were used for measuring the domains with three largest effect sizes (i.e. visual memory, psychomotor functioning, and attention and processing speed). Given that these tests required hand movement, the large effect sizes for these particular domains might be partly inflated by the existing motor disturbances. Despite this, the MS patients also significantly performed inferior to the controls in the PASAT, which purely required attention and was not influenced by motor dysfunction. When looked into some specific cognitive tests, it was found that the effect sizes were similar to those reported by the previous Western findings (Beatty, Goodkin, Monson, & Beatty, 1989; Beatty, Hames, Blanco, Paul, & Wilbanks, 1995; Beatty et al., 1995; Benedict, Cookfair et al., 2006; Benedict, Priore, Miller, Munschauer, & Jacobs, 2001; D'Esposito et al., 1996; Rao,

Leo, Bernardin, & Unverzagt, 1991; Sperling et al., 2001); for example, the BVMT-R, SDMT, PASAT, and JLO. It exemplified that the degrees of cognitive impairments caused by MS were similar between Chinese and Westerners.

It was further noted that the standard deviations of all tests except verbal fluency in the MS group were larger than those in the healthy controls, suggesting that there was a wider variability in cognitive skills among the patients. The remarkable discrepancies were observed in the Trail Making Test – Part A and Grooved Pegboard. Other characteristics such as age at 40 or older, female, greater physical disability measured by EDSS, and progressive types of MS were also correlated with worse cognitive performance (Haase, Lienemann, & Faustmann, 2008; Huijbregts et al., 2004; Litvan, Grafman, Vendrell, & Martinez, 1988; Prakash et al., 2008; S.M. Rao et al., 1987); therefore, it was reasonable that there was a wide variability among the patients. However, it was not statistically practical for the current study to divide the patients into subgroups based on the above characteristics for further comparisons because of small sample size and/ or uneven number of participants in each subgroup.

Overall, the current study provided evidence that cognitive impairment was also a common manifestation among the Chinese MS patients. Previous research had already found that cognitive dysfunctions could lead to significant functional impairment at home and work (Elsass & Zeeberg, 1983; Rao et al., 1991). However, it is difficult to identify cognitive impairment during face-to-face clinical examination (Fischer et al., 1994; Peyser, Edwards, Poser, & Filskov, 1980). It was strongly suggested that regular neuropsychological assessment for the Chinese MS patients is of importance.

6.2 Stressors caused by MS among Chinese patients

The current study made the first attempt to document the actual stressful situations caused by MS in the Chinese patients. Findings indicated that MS could elicit a complex array of stressors in both physical and psychosocial aspects to the patients. Consistent with previous qualitative research (Irvine, Davidson, Hoy, & Lowe-Strong, 2009; Malcomson et al., 2008), the current findings highlighted that the debilitating effects of the disease were pervasive and invaded every area in life such as physical, social, economic, and emotional. Patients struggled to make adjustment to all kinds of changes caused by physical problems such as employment status and social activities. Even though they had adjusted their lives, they were still threatened by illness uncertainty. Uncertain and unpredictable development of MS was the biggest challenge as this made the future planning extremely difficult. Also, this nature elicited lots of worries across different areas of life such as future of their families, economy, employment, interpersonal relationship, and reproduction. The unpredictable illness trajectory was shown to be associated with psychological distress like depression and anxiety (Mullins et al., 2001).

In addition, the current study established the stressor checklist of Chinese MS patient, which set as an anchor for future MS psychosocial research. There is still a huge room for MS study in Chinese context. The results were valuable and helpful in making clear to the local professionals, researchers, and service providers to understand the concerns, needs, and difficulties of the patients in Hong Kong. Indeed, it was very important to recognize the multifaceted stressors experienced by the patients. It was because this would inform future intervention program about relevant and beneficial coping methods, each of which might target at assisting the MS individuals in managing a specific stressor such as physical problem or any

psychosocial consequences of MS.

6.3 Stress, coping, and psychological adjustment

6.3.1 The direct effects of stress on depression and life satisfaction

The results supported hypothesis 1 that number of subjective stressful situations caused by MS and some illness parameters (conceptualized as objective stressors) would directly predict depressive symptoms and general life satisfaction above and beyond the effects of education and cognitive performance. It was in agreement with previous studies that patients who needed to face more stressful situations would have higher degree of depressive symptoms and life dissatisfaction (De Judicibus & McCabe, 2007; Johnson et al., 2007). In the current study, illness parameters in terms of number of recent symptoms and EDSS were predictive of depressive symptoms and life satisfaction respectively. It concurred with prior work that disease severity and physical disability had a positive relationship with depression (Johnson et al., 2007; Lynch et al., 2001; McIvor et al., 1984; Ryan et al., 2007).

6.3.2 The influences of coping processes on adjustment

Hypothesis 2 was partly confirmed by the findings that coping resources but not coping strategies were significantly and independently predictive of psychological adjustment even though the MS individuals were in the face of stress. Perceived social support was the independent predictor of depressive symptoms, while illness acceptance was the independent predictor of both depressive symptoms and general life satisfaction.

6.3.2.1 Coping strategies

The findings in the current study revealed that coping strategies associated with

neither depressive symptoms nor life satisfaction of the MS patients. This was in accord with McCabe and Di Battista (2004), who conducted a longitudinal study to estimate the predictive power of coping strategy on psychological adjustment among the individuals with MS. They found that, over a duration of 18-month, the depression level at time 2 was only predicted by its level at time 1. The usage of coping strategies at time 1 failed to account for any significant additional variances in adjustment, suggesting that there was a high stability of emotional response in the patients. It was contrary to previous studies which indicated that persons with MS who used emotional-focused coping such as wishful thinking and avoidance to deal with the illness were more likely to experience greater levels of depression and distress (Goretti et al., 2009; Lynch et al., 2001; McCabe et al., 2004; Pakenham, 1999; Pakenham, 2001). Meanwhile, Pakenham (1999) stressed that high levels of problem-focused coping strategies led to better psychological adjustment. One of the possible explanations for the conflicting results was that the coping scale – CWOC used in the current study was not specifically designed for clinical use. The coping strategy item stated in the scale might not directly address to the problems associated with MS. Moreover, the relationship of psychological adjustment with coping strategy would vary according to the category of MS-related stressor, although the support was weak (Pakenham et al., 1997). Unfortunately, there was no consistency between the antecedent coping studies about the type of stressor to which the MS participants referred when they filled in the coping strategy scale. Thus, this might lead to variations in the coping strategy-adjustment association.

6.3.2.2 The beneficial roles of coping resources

When it came to coping resources, the results confirmed the application of Lazarus and Folkman's stress and coping model in understanding psychological adjustment to

MS in the Chinese patients. Both perceived social support and illness acceptance were the useful coping resources in buffering the negative impact of stress on psychological well-being among the Chinese MS persons.

First of all, the current study found that perceived social support was able to explain additional variances in depression after controlling the effects of education, cognitive functioning, number of recent symptoms, and subjective stressors. Social support acted as an independent predictor of depression. It had beneficial role in adaptation to the illness. The patients with higher level of social support were less likely to develop depressive symptoms, even though they were in face of stress. Other past studies also concurred that social support had its unique contribution to predict depression beyond the influences of demographic and clinical characteristics (McCabe et al., 2004; Pakenham, 1999; Ryan et al., 2007). The importance of support received from others in the social network such as family and friends was, however, more salient in preventing development of depression rather than in promoting greater sense of life satisfaction. The current findings revealed that social support was not significantly associated with general life satisfaction. Instead, the MS-related stressors experienced by the patients had the strongest association, followed by disease severity, and cognitive performance. It was contradictive to the results obtained by Ryan et al. (2007) in which higher level of social support was associated with better life satisfaction.

The differential role of perceived social support in predicting depressive symptoms and satisfaction of life highlighted that subjective well-being was multidimensional as suggested by Lucas, Diener, and Suh (1996) and Ryan et al. (2007). Support provided by others was beneficial to affective well-being such as depression but not to cognitive-judgmental well-being like life satisfaction. Living with MS, the individuals often suffered from emotional distress due to many

unexpected and unfavourable changes in life. Both instrumental and emotional support was indeed very important to these individuals because various forms of support could address and fulfill their needs accordingly; for instance, persons with MS reported that social support was able to fulfill their emotional needs (Dilorenzo, Becker-Feigeles, Halper, & Picone, 2008; Fong, Finlayson, & Peacock, 2006). However, patients with MS were most concerned with the negative sequelae of the illness such as cognitive and functional impairments, role limitations, and emotional distress (Benito-León, Morales, Rivera-Navarro, & Mitchell, 2003; Rothwell, McDowell, Wong, & Dorman, 1997). In this sense, together with deterioration in physical health caused by MS, it was reasonable that social support could not increase patients' satisfaction in life. No matter how much support the patients obtained from their significant others, the adverse impact caused by the disease physically, psychosocially, and functionally was not erased with ease. As a result, when the patients judged their whole life, they tended to report lower life satisfaction when compared to the general population (Nortvedt, Riise, Myhr, & Nyland, 2000; Solari & Radice, 2001) and persons with other disabling disease (Hermann et al., 1996; Lankhorst et al., 1996).

Secondly, acceptance of illness was found to be a significant coping resource for the MS individuals to fight against the stress accompanied by the disease. The current study ascertained the importance of acceptance in accounting for additional variances in depression and general life satisfaction over and above the factors of demographics, cognitive functioning, disease severity, and subjective MS-related stressors experienced in life. It was suggested that those patients with increased level of acceptance tended to have less depressive symptoms and better satisfaction in life. Although empirical evidence supporting the association between illness acceptance and psychological adjustment among the MS persons was too limited thus far, the

results were still in line with the only one reviewed study (Dennison et al., 2010) and past qualitative studies (Kirkpatrick Pinson et al., 2009; Malcomson et al., 2008) which identified the protective role of acceptance for positive psychological outcomes. In fact, the prominent role played by acceptance in the Chinese patients with MS also fitted the Eastern philosophical teachings that coping with adversity is through changing one's mental or goal structure but not the stressors {Cheng, 2008 #832}. Acceptance of suffering, accepting life as a whole regardless of positive and negative aspects, and accepting whatever is given in life are considered to be appropriate responses for Chinese.

The concept of illness acceptance was somewhat similar to the accommodation mode, also known as flexible goal adjustment, which addressed the dynamics of goal striving throughout the lifespan (Brandtstädter & Greve, 1994; Brandtstädter & Renner, 1990). Flexible goal adjustment played an essential role in buffering the negative impact of functional declines and losses on psychological well-being in the persons with bodily handicap, impaired health, loss of sensory function, and chronic pain (Boerner, 2004; Heyl, Wahl, & Mollenkopf, 2007; Schmitz, Saile, & Nilges, 1996; Seltzer, Greenberg, Floyd, & Hong, 2004). Illness acceptance helped the individuals with MS diminish the unfavourable meaning of the disease and enabled them to accept, tolerate, and master the aversive consequences caused by the disease under impairment and limitation. Meanwhile, the accommodation mode facilitated the individuals to regain an overall sense of achievement under the situation appearing to be unchangeable and irreversible. Both of them emphasized that the afflicted individuals had to flexibly adjust their personal goals and frames of self-evaluation to situational constraints and to find positive meaning in life under undesirable circumstances. They indeed helped the individuals react positively to life experiences. According to Carver et al. (1993), while a stressor cannot be changed

easily and must be accommodated, acceptance of the stressor is particularly adaptive. Given that MS is not curable and its progressive nature to cause dysfunction in a variety of body systems, the individuals with MS usually have to live with the irreversible and adverse changes in different areas of life for lifetime. The results informed us that it would be more beneficial to psychological well-being when the MS individuals had learnt to accept their current conditions regardless of physically or psychosocially and to not expect these conditions to be altered somehow. It was crucial for them to integrate of the unwanted changes into their sense of self and way of life. Under some circumstances, they also had to flexibly change their life goals according to the status quo in order to maintain good psychological health.

6.4 The roles of cognition in coping

6.4.1 Predictors of coping strategies

In order to explore whether cognitive dysfunction was related to coping styles, the current study employed stepwise regressions to identify the neuropsychological predictors of the four following coping strategies – active problem solving, seeking social support, distancing, as well as wishful thinking. With accord to Goretti et al. (2010), the results indicated that both impairments in executive functioning and speed of information processing were uniquely linked to lesser preferences for active problem solving in the patients with MS. Active problem solving involves higher-order cognitive functioning including considering, planning, organizing, and implementing solutions. It was possible that deficits in executive functioning might reduce an individual's cognitive capacity to manage stressors associated with the disease using active coping mechanism. Moreover, it was likely that the patients with poorer performance on the PASAT had problems in sustaining attention to the

stressors and processing relevant information to combat against the stress. Thus, the patients had lesser cognitive resources associated with executive functioning and attention to resolve the problems actively. Secondly, similar to the persons with schizophrenia (Lysaker et al., 2004), the MS individuals exhibiting impairments in verbal memory tended to seek lesser social support when they encountered difficulties. It was postulated that verbal memory deficits caused the patients to have problems in acquiring, storing, and recalling complex verbal information, thoughts, and feelings, which, in turn, made them feel harder to communicate with others during the stressful periods. The social network bonding might be weakened by decreased effective communication. Thus, these patients were less likely to seek support from others. Likewise, the patients with poor verbal memory had a higher tendency to employ distancing as a method to deal with the stressors. It was wondered whether these patients were more difficult to access stored knowledge and remember any effective strategies which they might have used to combat against stress in the past, thereby leading to the choices of leaving the stressors alone. Lastly, wishful thinking was independent of cognitive deficits. It might be because wishful thinking did not significantly demand any cognitive activities. Of note, the above explanations for the association of cognitive deficits with coping strategies were speculative. The underlying mechanism of these linkages warranted further investigations; for instance, conducting in-depth interviews with the MS individuals with and without memory impairments to explore what made them to choose a certain kind of coping strategy over other strategies.

6.4.2 Significance of verbal memory in coping resources and positive psychological adjustment

Among all of the cognitive domains, verbal memory was the only one which exerted

influences on the association of coping resources with psychological adjustment. The significance of the indirect effects of stress and verbal memory deficits on depressive symptoms and life satisfaction through the coping resources was evaluated under path analysis, and the results supported hypothesis 3.

First of all, it was found that while number of MS-related stressful situation exerted a direct and positive influence on depressive symptoms, it was also partially mediated by illness acceptance. It agreed with the theoretical stress-coping concept of Lazarus and Folkman (1984) that the negative impact of stress could be alleviated through coping resource. Along with one previous quantitative study (Dennison et al., 2010), the current study established empirical evidence for the significance of illness acceptance in adjusting psychological well-being among the MS individuals. The patients who experienced more stressful situations tended to lower their acceptance of MS, resulting in depression and life dissatisfaction. It was noticed that, unlike illness acceptance, perceived social support did not bear a mediating role in the relationship between stress and psychological well-being. This difference might be attributed to the different nature of these two coping resources. Illness acceptance being a belief held by a patient was relatively more intra-individual when compared to perceived social support partly depending on perception of the patient and also partly the actual amount of support received from the social network which was relatively more inter-individual. When the patient encountered stressful situation, his/her own thoughts were more readily and directly to be affected by stress rather than their level of social support that depended on other's action. Under higher degree of stress, it was easier for the patient to develop negative thoughts and rebel MS, resulting in negative psychological adjustment. Social support, however, received from the social network might not instantly and directly vary as a function of stress. In view of these, these two coping resources bore a differential role in the association

of stress with psychological well-being.

Secondly, deficits in verbal memory might affect psychological adjustment indirectly through its effect on illness acceptance and social support. Full mediation was observed. That meant, it was impaired verbal memory's effect on the above two coping resources that was responsible for increased likelihood of depression and life dissatisfaction. Patients with poorer verbal memory were more likely to have decreased levels of illness acceptance and social support, both leading to more depressive symptoms and lower life satisfaction. In the previous work of Rabinowitz and Arnett (2009), the authors also revealed that coping was a mediator of the relationship between cognitive dysfunction and depression. In their work, coping was referred to coping strategy but not the coping resource as presented in the current study. Both studies extended our understanding of the underlying mechanism of the association between cognitive impairment and psychological adjustment in MS.

Perceived social support was found to be enhanced by higher functioning in verbal memory among the MS patients. It was because patients with better verbal memory were more easily to recall the type and level of support that they had received from the social network. As presented in the point of 6.3.2.2, social support could fulfill the psychological needs of the patients; therefore, there was a significant and positive relationship between verbal memory, perceived social support, and psychological adjustment.

When looked into how verbal memory influenced illness acceptance, it was speculated that acceptance might require cognitive resources in verbal memory, which is the ability to acquire, store, and retrieve information, thoughts and feelings. As mentioned in the point of 6.3.2.2, illness acceptance involved accepting the negative sequelae caused by MS in life and also mastering all of the unfavourable

consequences ranging from functional impairments to disruptions in life goals. One of the possible ways might be flexibly adjusting one's goals according to the current situation. When a patient found difficulty in achieving a pre-setting life goal especially when there was a new neurological symptom, s/he might have to replace this goal by setting another more reachable goal. This could help to maintain good level of psychological well-being. In such situation, verbal memory took a particular role in helping the patient memorize the reasons for not achieving the goals set in the very beginning. Later on, the patient was able to recall the relevant information when resetting a new and more appropriate goal to replace the old one. The process of goal adjustment might be continual in the lifespan among the patients with MS because MS could cause disturbances in a wide range of areas in daily living. For those patients with impaired memory, they might easily forget a particular goal which they previously set was not working out, but they might still repeatedly try to reach this unachievable goal, leading to negative emotional responses such as frustration, helplessness, and depressive symptoms. The memory-acceptance-psychological health relationship found in the current study would possibly be explained by the following condition: patients with better verbal memory would have more cognitive resources and benefits in flexibly making goal adjustments. When they found themselves still able to attain adjusted life goals under the limitation caused by MS, they might have a good sense of themselves reflected by reduced depressive symptoms and better life satisfaction, which, in turn, made them to accept their illness more easily.

6.5 Limitations

The current study highlighted several areas for future work. Firstly, the cross-sectional design could not assess the causality among neurocognitive deficits,

coping processes, and psychological adjustment. Future study involving longitudinal assessments of the above study variables was needed to replicate and ascertain the significance of the findings reported here. Secondly, comparisons of the patients' neuropsychological results were made based on the norms. Although they were matched demographically in aspects of age and education, IQ and socio-economic status which might also affect the neurocognitive performance were not matched due to unavailable access to these data. Thirdly, previously mentioned, the CWOC was not originally developed for clinical use especially for those individuals with chronic disease. Persons with MS often faced with a wide range of challenges, and they might possess different types of coping strategies to combat against the illness sequelae such as mobility problems, inability to work, and interpersonal changes. This coping measure might not be able to encompass part of the strategies which they utilized to encounter the stress. Thus, it was speculated that the CWOC did not truly reflect their coping abilities in real-life situation, leading to nil association with psychological adjustment as noted in the current study. As such, future research was recommended to adopt a coping instrument that was specially developed for MS population such as the one devised by Pakenham (2001) to elucidate the interaction between cognitive impairments, stress, coping, and adjustment. Lastly, there might well have been other confounding variables which interfered with the coping processes. For example, a few of past empirical research argued that personality traits of the MS persons were closely related to the choices of coping strategies (Goretti et al., 2009; Rätsep, Kallasmaa, Pulver, & Gross-Paju, 2000). The current findings, nonetheless, demonstrated the success in combining neuropsychological and psychosocial approaches to examine the cognitive predictors of coping in MS. It served as an anchor for future investigations that should build on the current theoretical work and move beyond to include more potential variables like

personality. It could advance our understanding of the relative contribution of relevant variables to positive psychological adjustment in MS.

6.6 Implications and future directions

The current study had distinct clinical implications. Firstly, it underscored the need for neuropsychological assessment and cognitive rehabilitation in the Chinese patients with MS. Neuropsychological impairment appeared to be relatively prevalent in Chinese MS patients in Hong Kong. The prevalence rates of MS patients to have cognitive decline varied from 43% to 70% in the Western countries (Benedict, Cookfair et al., 2006; Peyser et al., 1990). However, in our sample, 86.1% of them were found to be impaired on at least two or more cognitive domains. It has alerted local professionals including clinicians and researchers that proper, regular, and thorough neuropsychological assessment was indeed in need for the MS patients because cognitive deficits had profound negative impacts on functional abilities in daily lives (Higginson et al., 2000; Rao et al., 1991). Consistently, the current study revealed that deterioration in executive functioning and verbal memory significantly interfered with coping. Verbal memory was also associated with psychological well-being. It seemed that cognitive rehabilitation is important to the population of MS patients in order to promote effective coping mechanism and positive psychological adjustment. Local professionals have to take a role in providing appropriate cognitive skill training to the patients with impaired cognition to improve their quality of life. Previously, memory performance was shown to be improved among the patients with MS, particularly among those with moderate to severe memory deficits, in a cognitive rehabilitation training involving the teaching of “story memory technique” (Chiaravalloti, DeLuca, Moore, & Ricker, 2005). Specific

memory-enhancing techniques such as self-generated learning (Basso, Lowery, Ghormley, Combs, & Johnson, 2006; Chwastiak et al., 2002) and spaced learning (Goverover, Hillary, Chiaravalloti, Arango-Lasprilla, & DeLuca, 2008) were demonstrated to improve learning and memory of the patients with MS as well. In addition, Mattioli et al. (2010) argued that MS patients with cognitive deficits possessed the ability to significantly improve their performances on tests tapping attention, speed of information processing, and executive functioning after an intensive 3-month cognitive rehabilitation. They also showed depression improvement after the training. It proposed that sufficient amount of effective cognitive training was able to induce the additional activation of prefrontal and cingular cortices, leading to cognitive improvement. Besides of formal cognitive rehabilitation program offered to the patients, the clinicians and clinical researchers can also make use of techniques to compensate for the drawbacks associated with cognitive deficits in the patients (Basso et al., 2010). Cognitively comprised MS patients were found to be incapable of understanding the important information of disclosure about medical treatment or research, thereby affecting their ability to give consent. Nonetheless, provided with sufficient recognition cueing during disclosure, they showed level of information understanding that was equivalent to the patients with unimpaired cognition and control group. The technique of cueing was useful in facilitating those cognitively impaired patients to make decision on medical treatment and research participation.

Secondly, developing optimal coping is of paramount importance in the rehabilitation of MS. Given that MS is incurable and stressful, one of the best ways for the patients to adjust to it positively is to strengthen their resourcefulness to deal with its impacts in daily lives. In the current study, illness acceptance and social support were proved to be the core coping resources in promoting psychological

health even when the patients were in the face of stress. Future development of effective coping intervention should focus on the techniques to enhance patients' acceptance towards MS (e.g. developing positive reappraisal of the illness) and perception of social support (e.g. increasing appreciation of other's assistance). The significant role of social support in reducing the development of depression has highlighted the needs of support from others when the patients are walking the disease journey. Family members, caregivers, and friends are highly recommended to provide help and support as much as possible so as to help the patients adapt to MS more successfully. At the same time, clinicians should also always take cognitive deficits into serious consideration when they implement effective coping intervention to the patients. They must be aware that the outcomes may also vary as a function of cognitive deficits. To exemplify, the current study highlighted that dysfunction in verbal memory would deplete cognitive resources for the patients to accept MS and perceive the extent of social support, resulting in poor psychological adjustment. The result had crucial implication for how effective coping should be addressed and evaluated for those cognitively comprised MS patients.

To conclude, both training of comprised cognitive skills and coping with stress are the vital elements in rehabilitation of MS. To maximize the benefit, both of them should be included in the treatment program if necessary; for example, those patients with poor memory should be firstly educated some memory-enhancing techniques to improve memory, and subsequently be taught with the skills to increase the levels of illness acceptance and social support.

6.7 Conclusion

The study was the first systematic attempt to explore the relationships among neurocognition, stress, coping, and psychological adjustment among the individuals

with MS in a Chinese context. Application of the transactional model of stress and coping succeeded in this population. Specific cognitive domains played significant roles in the coping processes including preferences for strategies and levels of coping resources. Taken as a whole, assessment of neurocognition could yield valuable information about coping which was helpful to rehabilitation of MS. The current findings contributed to generate substantial knowledge in tailoring future interventions to enhance the MS individuals' coping effectiveness to manage stress for both Chinese and non-Chinese populations.

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Table 1. Stressful situations in daily lives reported by the Chinese patients with MS

Items
1. Unpredictability of illness trajectory
2. Poorer work performance
3. Fear of job loss
4. Disclosure of disease to others
5. Impact on social life
6. Economic problems
7. Worry about own future
8. Worry about family's future
9. Concerned about foetus's health
10. Reproduction difficulties
11. Others

Table 2. Component measures of the cognitive domain

Domain	Neuropsychological test measures
Verbal Memory	HKLLT Random condition 30-min delayed recall HKLLT Blocked condition 30-min delayed recall
Visual Memory	BVMT-R 25-min delayed recall
Executive Functioning	WCST-64
Attention & Information Processing Speed	Symbol Digit Modalities Test Trail Making Test - Part A PASAT-3 sec
Psychomotor Functioning	Grooved Pegboard dominant hand trial Grooved Pegboard non-dominant hand trial
Verbal Fluency	Animal fluency Action fluency
Visuospatial Ability	Benton Judgement of Line Orientation

Note. HKLLT = Hong Kong List Learning Test; BVMT-R = Brief Visuospatial Memory Test-Revised; WCST-64 = Wisconsin Card Sorting Test-64 Card Version; PASAT-3 sec = Paced Auditory Serial Addition Task – 3 second interval.

Table 3. Descriptive statistics of neuropsychological test performance, stress and coping-related variables, and psychological well-being of the MS patients ($n = 72$)

Outcome measures	Mean	(SD)
<i>Neuropsychological tests</i>		
HKLLT random condition 30-min delayed recall	7.57	(3.42)
HKLLT blocked condition 30-min delayed recall	9.77	(5.04)
BVMT-R 25-min delayed recall	7.56	(3.11)
SDMT	43.15	(15.28)
WCST-64 – total correct	36.22	(12.70)
WCST-64 – perseverative errors	14.65	(10.19)
TMT – part A	67.06	(61.43)
Grooved Pegboard – dominant hand	90.51	(39.95)
Grooved Pegboard – non-dominant hand	100.94	(53.38)
Verbal fluency – animal	16.28	(5.03)
Verbal fluency – action	11.38	(4.54)
PASAT-3 sec	26.77	(11.92)
Benton JLO – Form H	20.68	(5.16)
<i>Stress and coping-related variables</i>		
Number of stressors induced by MS	5.81	(2.19)
Acceptance of Chronic Health Conditions Scale	32.49	(5.40)
Social Provision Scale	71.77	(9.75)
CWOC – Active problem solving	7.35	(3.06)
CWOC – Distancing	4.68	(2.61)
CWOC – Seeking social support	6.01	(3.34)
CWOC – Wishful thinking	5.42	(2.73)
<i>Psychological well-being</i>		
Beck Depression Inventory – II	14.56	(10.53)
Satisfaction with Life Scale	24.61	(8.16)

Note. SD = Standard deviation; HKLLT = Hong Kong List Learning Test; BVMT-R = Brief Visuospatial Memory Test-Revised; SDMT = Symbol Digit Modalities Test; WCST-64 = Wisconsin Card Sorting Test-64 Card Version; TMT = Trail Making Test; PASAT-3 sec = Paced Auditory Serial Addition Task – 3 second interval; JLO = Judgement of Line Orientation; CWOC = Chinese Way of Coping Questionnaire.

Table 4. Comparison of raw scores on neuropsychological tests between the MS and healthy control groups using independent *t*-test

Cognitive measures	MS		Healthy control		<i>t</i> -value	Cohen's <i>d</i>
	Mean	<i>SD</i>	Mean	<i>SD</i>		
Verbal memory						0.79
HKLLT RC 30-min delayed recall	7.57	3.42	10.22	2.98	-5.93*	0.83
HKLLT BC 30-min delayed recall	9.77	5.04	12.72	2.38	-5.94*	0.75
Visual memory						1.20
BVMT-R 25-min delayed recall	7.56	3.11	10.54	1.61	-9.47*	1.20
Executive Functioning						0.77
WCST-64 total correct	36.22	12.70	45.14	11.87	5.14*	0.73
WCST-64 – perseverative errors	14.65	10.19	8.14	5.24	6.32*	0.80
Attention & Information Processing Speed						0.89
SDMT	43.15	15.28	52.76	10.62	-5.47*	0.73
TMT – part A	67.06	61.43	31.07	11.28	7.02*	0.81
PASAT-3 sec	26.77	11.92	38.59	8.69	-8.37*	1.13
Psychomotor Functioning						0.96
Grooved Pegboard – dominant hand	90.51	39.95	61.51	8.77	8.55*	1.00
Grooved Pegboard – non-dominant hand	100.94	53.38	65.99	10.38	7.77*	0.91

Table 4 (Cont'd). Comparison of raw scores on neuropsychological tests between the MS and healthy control groups using independent *t*-test

Cognitive measures	MS		Healthy control		<i>t</i> -value	Cohen's <i>d</i>
	Mean	<i>SD</i>	Mean	<i>SD</i>		
Verbal Fluency						0.77
Animal	16.28	5.03	19.13	4.47	-4.28*	0.60
Action	11.38	4.54	15.87	5.07	-6.04*	0.93
Visuospatial Ability						0.55
Benton JLO – form H	20.68	5.16	23.15	3.72	-4.07*	0.55

Note. *SD* = Standard deviation; HKLLT = Hong Kong List Learning Test; BVMT-R = Brief Visuospatial Memory Test-Revised; WCST-64 = Wisconsin Card Sorting Test-64 Card Version; SDMT = Symbol Digit Modalities Test; TMT = Trail Making Test; PASAT-3 sec = Paced Auditory Serial Addition Task- 3 second interval; JLO = Judgement of Line Orientation.

**p* < 0.001.

Table 5. Significant correlates' coefficients (r) of psychological well-being of the MS participants ($n = 72$)

	Depressive symptoms (BDI-II)	Life satisfaction (SWLS)
Education years	-0.32*	<i>n.s.</i> ($p = 0.11$)
Number of recent symptoms	0.30*	<i>n.s.</i> ($p = 0.10$)
EDSS	<i>n.s.</i> ($p = 0.03$)	-0.46**
Number of subjective stressors	0.36**	-0.33**
HKLLT BC 30-min delayed recall	-0.47**	0.38*
SDMT	-0.43**	0.45**
Illness acceptance	-0.52**	0.48**
Social support	-0.54**	0.37**

Note. EDSS = Extended Disability Status Scale; HKLLT BC = Hong Kong List Learning Test Blocked Condition; SDMT = Symbol Digit Modalities Test; BDI-II = Beck Depression Inventory-II; SWLS = Satisfaction with Life Scale; p = significance level.

* $p \leq 0.01$; ** $p \leq 0.001$; *n.s.* = non-significant.

Table 6. Stepwise regressions with cognitive measures regressed on coping strategies of active problem solving, distancing, and seeking social support ($n = 72$)

Coping strategy	Predictors	R^2	B	t	sr^2	F	ΔR^2	ΔF
Active problem solving	Model 1	0.17				11.34**	-	-
	PASAT-3 sec		0.10	3.37**	0.17			
	Model 2	0.23				8.03**	0.06	4.08*
	PASAT-3 sec WCST-64 – perseverative error		0.07 -0.08	2.08* -2.02*	0.06 0.06			
Distancing	Model 1	0.35				33.16**	-	-
	HKLLT BC 30-min delayed recall		-0.28	-5.76**	0.35			
	Model 2	0.39				19.04**	0.04	4.01*
	HKLLT BC 30-min delayed recall HKLLT RC 30-min delayed recall		-0.18 -0.20	-2.67** -2.00*	0.07 0.06			
Seeking social support	Model 1	0.21				17.01**	-	-
	HKLLT BC 30-min delayed recall		0.29	4.12**	0.21			

Note. PASAT-3 sec = Paced Auditory Serial Addition Task – 3 sec interval; HKLLT RC/ BC = Hong Kong List Learning Test Random Condition/ Blocked Condition; WCST -64 = Wisconsin Card Sorting Test-64 Card Version; B = unstandardized beta coefficient; t = t -value; sr^2 = unique squared semipartial correlation; F = F -value; ΔR^2 = Change in R^2 ; ΔF = Change in F -value.

* $p \leq 0.05$; ** $p \leq 0.01$.

Table 7. Hierarchical multiple regression analyses of the effects of demographics, cognitive functioning, stressors, and social support on depressive symptoms ($n = 72$)

Predictors	Depressive symptoms (BDI-II)						
	R^2	B	t	sr^2	F	ΔR^2	ΔF
Model 1	0.17				4.52*	-	-
Education years		-0.82	-1.66	0.03			
HKLLT BC 30-min delayed recall		-0.15	-0.49	0.00			
SDMT		-0.15	-1.45	0.03			
Model 2	0.30				5.44**	0.13	5.82*
Education years		-0.81	-1.70	0.03			
HKLLT BC 30-min delayed recall		-0.09	-0.30	0.00			
SDMT		-0.16	-1.54	0.03			
Number of recent symptoms (objective stressor)		0.68	1.00	0.01			
Number of MS-induced stressors in daily life (subjective stressor)		1.47	2.68*	0.10			
Model 3	0.43				7.76**	0.13	13.88**
Education years		-0.29	-0.64	0.00			
HKLLT BC 30-min delayed recall		0.33	1.14	0.01			
SDMT		-0.15	-1.62	0.02			
Number of recent symptoms		0.76	1.24	0.01			
Number of MS-induced stressors in daily life		1.39	2.97*	0.07			
Social support		-0.49	-3.73**	0.13			

Note. HKLLT BC = Hong Kong List Learning Test Blocked Condition; SDMT = Symbol Digit Modalities Test; BDI-II = Beck Depression Inventory-II; B = unstandardized beta coefficient; t = t -value; sr^2 = unique squared semipartial correlation; F = F -value; ΔR^2 = Change in R^2 ; ΔF = Change in F -value.

* $p \leq 0.01$; ** $p \leq 0.001$.

Table 8. Hierarchical multiple regression analyses of the effects of cognitive functioning, stressors, and social support on general life satisfaction ($n = 72$)

Predictors	General life satisfaction (SWLS)						
	R^2	B	t	sr^2	F	ΔR^2	ΔF
Model 1	0.09				3.19		
HKLLT BC 30-min delayed recall		0.13	0.55	0.00			
SDMT		0.13	1.57	0.03			
Model 2	0.21				4.27*	0.12	4.98*
HKLLT BC 30-min delayed recall		0.15	0.63	0.01			
SDMT		0.07	0.74	0.01			
EDSS (objective stressor)		-0.75	-2.54	0.03			
Number of MS-induced stressors in daily life		-1.05	-2.49*	0.08			
Model 3	0.26				4.54**	0.05	4.63
HKLLT BC 30-min delayed recall		-0.07	-0.27	0.00			
SDMT		0.03	0.38	0.00			
EDSS		-0.90	-1.88	0.04			
Number of MS-induced stressors in daily life		-0.98	-2.39	0.07			
Social support		0.24	2.15	0.05			

Note. HKLLT BC = Hong Kong List Learning Test Blocked Condition; SDMT = Symbol Digit Modalities Test; EDSS = Extended Disability Status Scale; SWLS = Satisfaction with Life Scale; B = unstandardized beta coefficient; t = t -value; sr^2 = unique squared semipartial correlation; F = F -value; ΔR^2 = Change in R^2 ; ΔF = Change in F -value.

* $p \leq 0.01$; ** $p \leq 0.001$.

Table 9. Hierarchical multiple regression analyses of the effects of demographics, cognitive functioning, stressors, and illness acceptance on depressive symptoms ($n = 72$)

Predictors	Depressive symptoms (BDI-II)						
	R^2	B	t	sr^2	F	ΔR^2	ΔF
Model 1	0.17				4.52*	-	-
Education years		-0.82	-1.66	0.03			
HKLLT BC 30-min delayed recall		-0.15	-0.49	0.00			
SDMT		-0.15	-1.45	0.03			
Model 2	0.30				5.44**	0.13	5.82*
Education years		-0.81	-1.70	0.03			
HKLLT BC 30-min delayed recall		-0.09	-0.30	0.00			
SDMT		-0.16	-1.54	0.03			
Number of recent symptoms (objective stressor)		0.68	1.00	0.01			
Number of MS-induced stressors in daily life (subjective stressor)		1.47	2.68*	0.10			
Model 3	0.37				6.29**	0.08	7.68*
Education years		-0.75	-1.66	0.03			
HKLLT BC 30-min delayed recall		0.06	0.20	0.00			
SDMT		-0.11	-1.13	0.01			
Number of recent symptoms		0.90	1.38	0.02			
Number of MS-induced stressors in daily life		0.84	1.47	0.02			
Illness acceptance		-0.63	-2.77*	0.11			

Note. HKLLT BC = Hong Kong List Learning Test Blocked Condition; SDMT = Symbol Digit Modalities Test; BDI-II = Beck Depression Inventory-II; B = unstandardized beta coefficient; t = t -value; sr^2 = unique squared semipartial correlation; F = F -value; ΔR^2 = Change in R^2 ; ΔF = Change in F -value.

* $p \leq 0.01$; ** $p \leq 0.001$.

Table 10. Hierarchical multiple regression analyses of the effects of cognitive functioning, stressors, and acceptance of illness on general life satisfaction ($n = 72$)

Predictors	General life satisfaction (SWLS)						
	R^2	B	t	sr^2	F	ΔR^2	ΔF
Model 1	0.09				3.19		
HKLLT BC 30-min delayed recall		0.13	0.55	0.00			
SDMT		0.13	1.57	0.03			
Model 2	0.21				4.27*	0.12	4.98*
HKLLT BC 30-min delayed recall		0.15	0.63	0.01			
SDMT		0.07	0.74	0.01			
EDSS (objective stressor)		-0.75	-2.54	0.03			
Number of MS-induced stressors in daily life		-1.05	-2.49*	0.08			
Model 3	0.29				5.20**	0.08	7.24*
HKLLT BC 30-min delayed recall		0.04	0.28	0.00			
SDMT		0.03	0.37	0.00			
EDSS		-0.75	-1.61	0.03			
Number of MS-induced stressors in daily life		-0.59	-1.36	0.02			
Illness acceptance		0.49	2.69*	0.08			

Note. HKLLT BC = Hong Kong List Learning Test Blocked Condition; SDMT = Symbol Digit Modalities Test; EDSS = Extended Disability Status Scale; SWLS = Satisfaction with Life Scale; B = unstandardized beta coefficient; t = t -value; sr^2 = unique squared semipartial correlation; F = F -value; ΔR^2 = Change in R^2 ; ΔF = Change in F -value.

* $p \leq 0.01$; ** $p \leq 0.001$.

Table 11. Correlation matrix among scores of subjective MS-induced stressors, verbal memory, illness acceptance, social support, depressive symptoms, and general life satisfaction

	No. of stressors	HKLLT-BC delayed recall	ACHC	SPS	BDI-II
No. of stressors	-				
HKLLT-BC delayed recall	0.00	-			
ACHC	-0.42**	0.45**	-		
SPS	-0.09	0.48**	0.40**	-	
BDI-II	0.36**	-0.47**	-0.52**	-0.54**	-
SWLS	-0.33**	-0.38*	0.48**	0.37**	-0.62**

Note. HKLLT-BC = Hong Kong List Learning Test Blocked Condition; ACHC = Acceptance of Chronic Health Conditions Scale; SPS = Social Provisions Scale; BDI-II = Beck Depression Inventory-II; SWLS = Satisfaction With Life Scale.

* $p < 0.01$; ** $p < 0.001$.

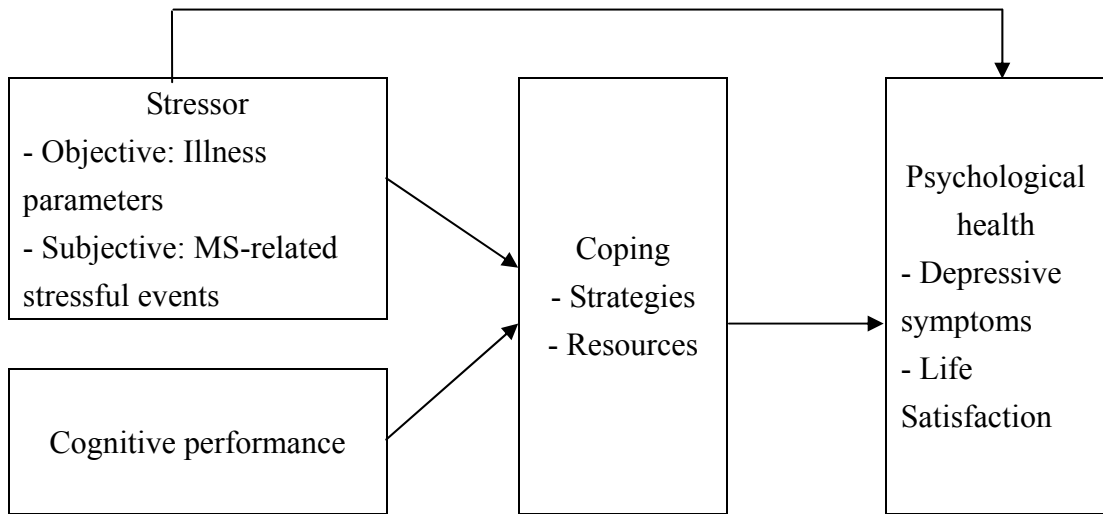


Figure 1. The hypothesized theoretical model in the current study

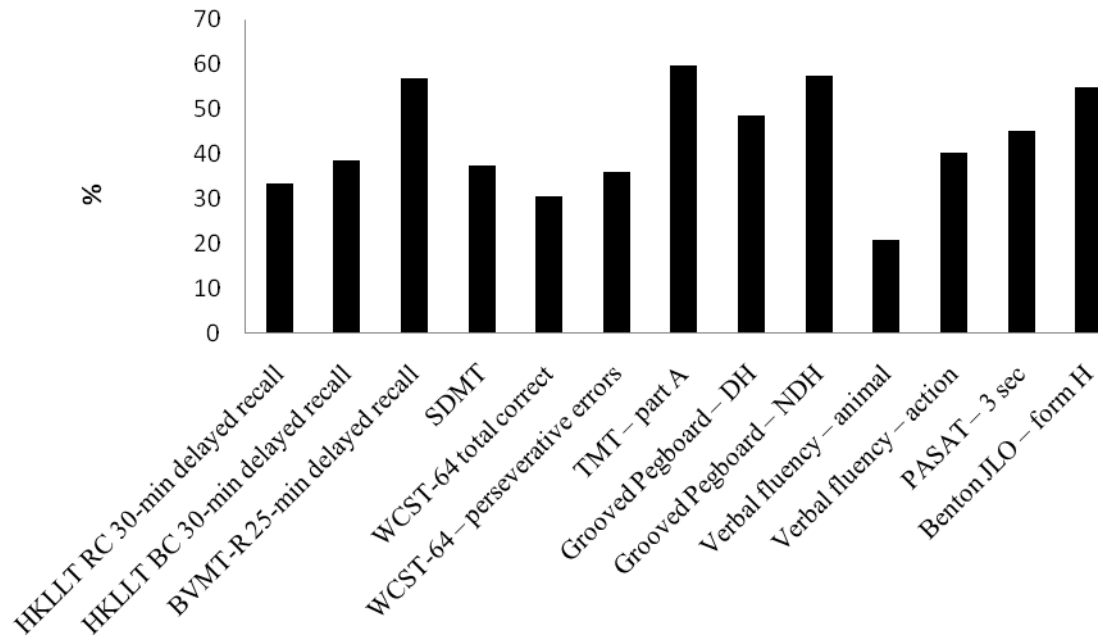


Figure 2. Percentages of MS patients impaired in neuropsychological tests using a cut-off z -scores of -1.5 on the basis of the local norm

Note. HKLLT = Hong Kong List Learning Test; RC = Random condition; BC = Blocked condition; BVMT-R = Brief Visuospatial Memory Test-Revised; SDMT = Symbol Digit Modalities Test; WCST-64 = Wisconsin Card Sorting Test-64 Card Version; TMT = Trail Making Test; DH = dominant hand; NDH = non-dominant hand; PASAT-3 sec = Paced Auditory Serial Addition Task – 3 second interval; JLO = Judgement of Line Orientation.

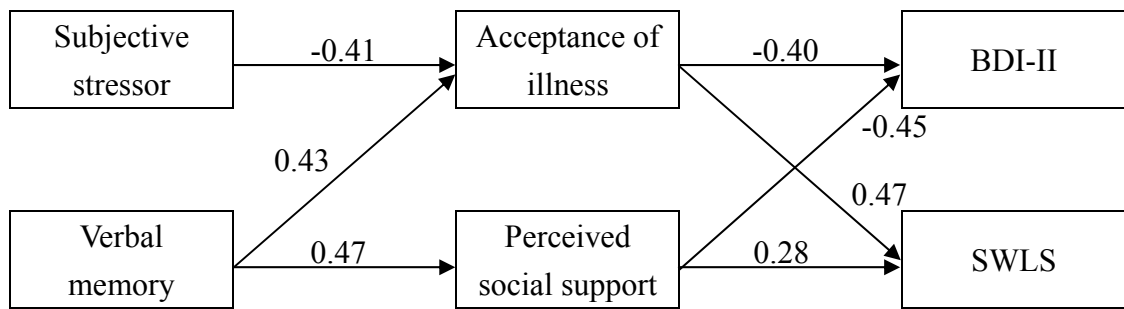


Figure 3. The hypothesized model (Model 1) assuming full medication effects of coping resources on psychological health. The fit indices were as follows: $\chi^2(8) = 15.35$, $p = 0.05$, NNFI = 0.87, CFI = 0.93; GFI = 0.92, RMSEA = 0.13.

Note. BDI-II = Beck Depression Inventory-II; SWLS = Satisfaction with Life Scale.

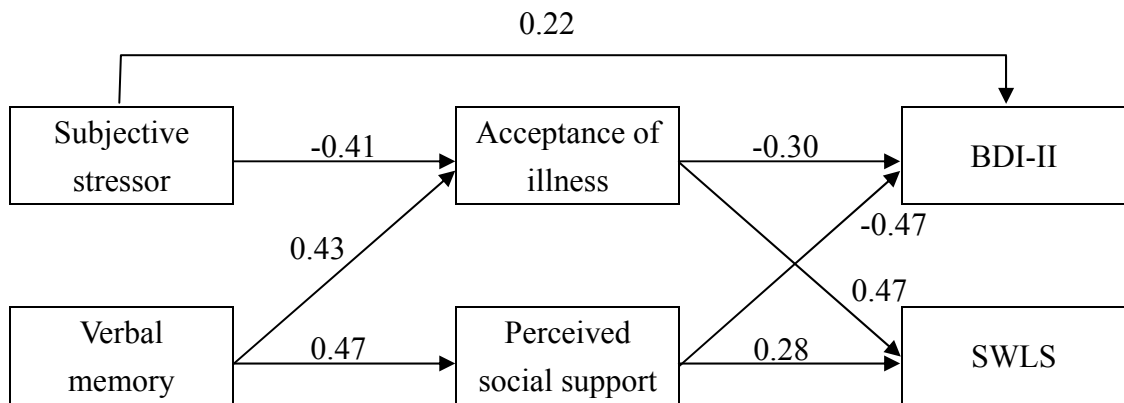


Figure 4. The final model (Model 2) illustrating (1) partial mediation effects of illness acceptance on the relationship between stressor and psychological health and also (2) full mediation effects of social support and acceptance on the association of verbal memory with psychological health. The fit indices were as below: $\chi^2(7) = 11.07$, $p = 0.14$, NNFI = 0.92, CFI = 0.96; GFI = 0.94, RMSEA = 0.09.

Note. BDI-II = Beck Depression Inventory-II; SWLS = Satisfaction with Life Scale.