The impact of social support on perceived well-being of stroke survivors

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Abstract

Purposes: To develop the therapeutic nature of nursing in stroke rehabilitation, professional nurses need to consider recovery indicators in a more holistic approach. This study aimed to capture a health-oriented picture about stroke recovery as well as to explore whether social support plays a role in a stroke survivor's perceived well-being in the first six months after a stroke. Specific objectives of the study included: (1) to explore the perceived well-being of stroke survivors (in functional perspective, emotional perspective, social aspects of living and life satisfaction) immediately after the acute phase of stroke and six months later; (2) to investigate the change of perceived well-being of stroke survivors in the first six months following a stroke; (3) to investigate the role of social support on perceived well-being of stroke survivors.

Method: A six-month prospective design was adopted. Stroke survivors who met the selection criteria and had their diagnosis confirmed by medical practitioners were recruited to the study. Written informed consent was obtained prior to the data collection. The data was collected through face-to-face interview and physical assessment with two phases of data collection immediately after the acute phase of stroke and six months later. A majority of dependent variables and independent variables were measured. Open-ended questions were included to supplement information for gaining better understanding of perspectives of well-being as well as the situation-specific social support availability and utilisation.

Results:

1. In regard to the perceived well-being of stroke survivors, phase one findings indicate that the majority of the stroke survivors were dependent, to some degree, on others for activities of daily living. The majority of subjects were reported to have a depressive mood and were dissatisfied with their current physical health status and self-care ability.
2. There was significant improvement in the perceived well-being six months after the stroke. The subjects reported improvement in functional status, emotional status and life satisfaction. Nonetheless, in view of the participation in social and leisure-time activities, findings from this study show that these activities after the stroke tend to be homebound. The majority of the subjects could not return to their premorbid vocational status, social and leisure-time activities.
3. In the first six months after the stroke, different types of social support were available, including emotional support, tangible support, informational support and social companionship. Findings from this study further support previous findings that social support is situation-specific and changes with the time course of stroke recovery.
4. Social companionship was found to be a common predictor to the perceived well-being of the stroke survivors in the first six months after the stroke. Other important

predictive factors included tangible support, visual impairment, co-existing illness(es) and premorbid family role.

Conclusion: Findings from this study support the view that stroke recovery does not merely refer to the restoration of physiological function to the maximum potential. It also includes the ability to live independently and the psychological adaptation to the stroke, as well as continuing to participate in and contribute to the society. In assessing stroke recovery, apart from the functional parameters, stroke survivors' emotional status, participation in social and leisure-time activities, as well as life satisfaction all need to be considered. In addition, the findings of this study further emphasise that social support in the form of social companionship as well as practical help and assistance were found to have a significant impact on the perceived well-being of the stroke survivors in the first six months after the stroke. These findings provide useful information on the therapeutic nature of nursing in stroke rehabilitation. Specifically, this includes the identification and mobilisation of support resources from the stroke survivors' natural support networks, as well as the coordination of services to supplement needed resources so as to enhance the optimal level of health and well-being of stroke survivors throughout the course of recovery.

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

The occurrence of stroke is unexpected and traumatic. Those who survive the acute phase of stroke often live with irrational fears of death, insanity, disfigurement and loss of physical function. Furthermore, they have to face the socio-cultural implications of disability and experience a loss of independence in self-care, dignity and role alterations. Despite the policy claimed by the Government, Hong Kong still lacks an integrated service to provide for stroke survivors, particularly in the post-hospitalisation phase of care. As community-based stroke rehabilitation in Hong Kong is in its infancy, challenges and obstacles are likely to continue to surface in the years ahead. Meanwhile, in 1991, the Department of Social Welfare in Hong Kong claimed that every effort will be made to assist stroke survivors to achieve their optimal well-being and participate fully in the activities of the socio-cultural system of which they are an integral part. The readiness of nurses to take up these new challenges both in hospitals and the community will help build success. However, the rehabilitation needs of stroke survivors are unlikely to be well served unless gaps in the body of knowledge about stroke recovery and practice issues are addressed.

The first challenge is to turn the question: "How bad is the stroke?" into the question "How good is a 'good' recovery?" Ebrahim (1990), Bronstein (1991) and Whisnant

(1993) suggested useful approaches to consider recovery outcomes at different points in the natural history of stroke. At onset, survival is paramount. Later, neurological impairment and residual functional ability gain more attention. Such information may be useful for physicians and therapists to assess the progress of rehabilitation and treatment effectiveness. Nevertheless, physical parameters are only some of the recovery outcome indicators and cannot adequately inform and evaluate nursing interventions. There is a need to explore stroke survivors' perceptions of their own health and well-being. Patient-centred, health-oriented stroke outcome indicators are considered to be complementary to traditional outcome measure (Ebrahim, 1990 and Bronstein, 1991). Only with such indicators can nurses give priority to interventions that result in the best possible well-being for stroke survivors at different stages of recovery.

Second, the concept of rehabilitation has long been evolved from the World Health Organization's (1984) "impairments, disabilities and handicaps model". However, impairments, disabilities and handicaps are not necessarily in a linear relationship. Not infrequently, the distinction between disability and handicap seems unnecessary. As an illustration, a stroke survivor may be left with no disability, but having a stroke leads to the loss of livelihood (a severe handicap) because his/her family responsibility of looking after a grandson is taken away. Similarly, some impairment may cause disability but not necessarily handicap. A stroke may cause a person to be unable to walk and become chair-bound, but the provision of wheelchair and social facilities permits the person to continue leading a productive life. Hence, the model is not a complete description of the effects of a disease. It is much more likely that other factors such as personality, wealth and social support will operate to either reduce or increase the impact of the disease on an individual's perceived well-being. Researchers, clinicians and administrators, must explore these intervening factors when planning rehabilitative care following stroke.

Third, having been confronted by an unexpected and traumatic illness stroke survivors always experience a strong sense of personal inadequacy and powerlessness (Doolittle, 1988; Ebrahim, 1990). The ability to use available resources contributes to a sense of power but stroke survivors tend not to be able to avail themselves of available resources (Mok-Suen, 1998). Rehabilitation nurses must realise this phenomenon and mobilise available support or introduce new resources when needed. As the size of the social network may not accurately indicate the availability of support, a dynamic and systematic way of assessing the individual's support system must be explored. This in turn can provide the spur to look for ways of more cost-effective community-based rehabilitation that have been neglected. They may hold the key to improving stroke survivors' well-being throughout their long process of recovery.

1.2 Background to the study

Several issues relating to stroke are discussed, including the epidemiological pattern of stroke in Hong Kong, the cost of stroke, current stroke services in Hong Kong and the contribution of nursing to stroke rehabilitation. It is envisaged that the discussion might reveal the impact of a stroke on a stroke survivor, as well as how stroke care and service are provided in the local context of nursing.

1.2.1 Epidemiology of stroke in Hong Kong

Currently, stroke is the fourth leading cause of death in Hong Kong and the number is rising as the population ages (Department of Health, 1996). The crude mortality rate has risen from 44.2 per 100,000 population in 1961 to peak at 62.7 per 100,000 population in 1981. In the 1990's, there was a gradual downward trend. The crude mortality rate in 1995 was 53.8 per 100,000 population (Department of Health, 1996). In 1996, 19,884 people with cerebrovascular disease were treated in public hospitals and 3,102 died of the disease in the same year (Hospital Authority, 1997).

The proportion of different subtypes of stroke varies from country to country. Research findings have shown that non-Caucasians suffer more vascular disease than Caucasians. About 30% of Chinese stroke victims suffer from haemorrhagic stroke as compared to 5% to 20% in Western countries (Tacey and Black, 1995). In Hong Kong, ischaemic stroke constitutes more than 50% of stroke victims. Among these, 30% are due to lacunar infarcts (Mok, et al., 1997). Similar findings were also noted in the Shatin Stroke Registry in 1989 (Kay, et al., 1992).

When reviewing the age specific mortality rate, there appears to be a substantial decline in mortality in all ages. Nonetheless, stroke remains one of the most important causes of chronic morbidity and acquired disability. The survival, disability and place of residence at 3 and 20 months after stroke were assessed by Woo, Yuen, Kay and Nicholls (1992). Their findings showed that older stroke survivors had higher institutionalization rates and a greater decline in functional ability during the long-term follow up (Woo, et al., 1992). In addition, the care of stroke survivors is considered a heavy burden for most caregivers both at home or in institutions. The need for social support to both stroke survivors and their caregivers is pressing (Mok, et al., 1997).

1.2.2 The cost of stroke

As the aetiology, pathogenesis and the associated possible consequences differ among the different types of stroke, a general description of the impact of stroke is difficult, if not impossible. The impact of stroke can vary with the degree of neurological impairment, the resulting disability and handicap, the stroke survivor's perception of his/her functional loss and disability, the burden to the family and the cost to society (Ebrahim, 1990).

The impact of stroke at an individual level can be elaborated by the World Health Organization's (1984) classification of impairments, disabilities and handicaps. The impairment resulting from a stroke can be assessed in terms of the location of the stroke, the size of the lesion(s) or the extent and severity of neurological damage. The disability of stroke can be measured by the inability to walk, to climb stairs or to self-care. Handicap can be assessed by the impact on work, enjoyment of life and usual social engagements. As an illustration, motor impairment may lead to difficulty walking outdoors, which in turn may lead to the handicap of not being able to go to work or meet friends. A recent survey by the Hospital Authority on psychological aspects of life demonstrated that stroke survivors were ranked the worst for psychological well-being, compared with eleven other chronic illness and disability groups (Poon, 1997). A general impression reported by the stroke survivors indicated that it was very hard to relearn all the things that they used to take for granted. No end was in sight. The sense of identity was assaulted by changes in the body and its functional performance (Poon, 1997; Chang and Mackenzie, 1998). The inability to become independent in self-care leads to further loss of self-image, sense of confidence and dignity. These all involve tangible and intangible cost to the stroke survivors.

At the family level, stroke survivors' physical disabilities impose a considerable burden on the family caregivers (Brereton, 1999). In keeping with world trends, Hong Kong is moving towards de-institutionalisation and community care. Together with the strong sense of Confucian culture to support family members, family care (or home care) is considered an important "virture" in the care of stroke survivors in Hong Kong. Family members bear some of the shifted responsibilities for the community care of stroke. Stroke care at home is particularly demanding because caregivers' stress arises not only from their heavy and often relentless responsibilities, but also from the emotional burden arising from stroke survivors (Hodgson, Wood and Langton-Hewer, 1996). Stroke survivors experience a strong sense of personal inadequacy and powerlessness when they are being confronted by the disease. A stroke survivor may transfer his/her emotional frustrations onto the family caregiver who is usually the spouse or an immediate family member. Many research findings show that long-term family care for stroke survivors affects the physical and psychosocial well-being of the family caregiver, who may eventually become the second patient (Hodgson, Wood and Langton-Hewer, 1996). Economic burden to the family can also be easily evidenced, particularly when the stroke survivor used to be the breadwinner in the family. In addition, due to the caregiving responsibility, it is not uncommon to find that the caregiver has to quit his/her work to look after the stroke survivor. This further stresses the financial situation of the family.

The social cost of stroke is considerable. Traditionally, medical services in Hong Kong are based on an institutional model. However, the cost of hospitalisation has been increasing. The average cost per hospital bed per day has increased by 43% since 1989. Both acute beds and rehabilitation beds for stroke are in short supply. With the hospital policy on reducing hospital length of stay, the "revolving door phenomenon" is frequently seen. Chan, Ho, Chau and Ng (1996) highlighted three aspects of this phenomenon: (1) frequent re-admission for preventable complications such as pressure sores, urinary tract infection, contracture requiring costly follow-up treatment; (2) increased demand on other social services such as long-term care in infirmary or nursing home care due to family caregivers' inability to cope with home care; (3) other social problems, such as strained family relations and poor physical health of the family caregivers, providing a further drain on the medical and social services.

1.2.3 Stroke care services in Hong Kong

In the light of the tremendous costs of stroke, both the Hong Kong Government and health professionals are seeking effective and efficient management approaches to stroke rehabilitation. It is generally agreed that the stroke care process does not finish with the end of the acute episode of the illness. Rehabilitation aims to restore an individual's functional ability to his/her maximum potential so that he/she can live independently and continue to participate in the community (Department of Social Welfare, 1991). As part of the commitment to improving services in Hong Kong, the first White Paper on rehabilitation entitled "Integrating the Disabled into the Community: A United Effort" was published as early as 1977.. Since then, there has been a significant expansion of rehabilitation services. In January 1991, the Government appointed a Working Party on Rehabilitation Policies and Services. Apart from sensory impairment and mental illness, the Working Party further broadened the scope of rehabilitation services to the chronically ill and visceral disability, among which stroke was included as one of the major categories. In conformity to the Government Policy, the Hospital Authority also placed greater emphasis on rehabilitation services in its 1998/99 Annual Plan (Hospital Authority, 1998). A number of approaches were proposed and piloted. These included establishment of stroke units in acute settings, improving the existing services provision at extended care hospitals and developing a centre of excellence for stroke rehabilitation (Hospital Authority, 1998). Nevertheless, as yet, there has been no general agreement on how best to manage stroke in terms of the provision of stroke care services.

The traditional provision through in-patient rehabilitation services has its strengths but also its weaknesses. The hospital-dominated health care delivery was criticised in the recent report by the Harvard Team (1998) for not being able to manage the number of chronically ill patients and their needs. In the context of stroke care and services in Hong Kong, the concept of community-based health care delivery in stroke rehabilitation has gained more attention in recent years. Unfortunately, under the current hospital-dominated funding model, community-based care has suffered from insufficient status and financial support (The Harvard Team, 1998). Taking this into consideration, there is no doubt that Hong Kong is and will continue to be experiencing significant shifts to the community-based health care delivery model. Rehabilitation nurses must be able to recognise the potential and actual policy changes and their impact on nursing service delivery in the light of the needs and benefits of their clients throughout the wellness-illness continuum.

1.2.4 Nursing contributions in stroke rehabilitation

Role and function of rehabilitation nursing in stroke care

Stroke rehabilitation involves an interdisciplinary team approach, comprising the stroke survivor, his/her family, physical therapists, occupational therapists, nurses, social workers and rehabilitation physicians. It is generally agreed that nurses are important members of the team, as nursing is required for stroke survivors twenty-four hours a day, seven days a week (Gibbon, 1991; Bronstein, 1991; Hartmann and Cordes, 1998). Nurses always claim to have diverse roles, for example care provider, coordinator, collaborator and case manager. Despite this, the actual contribution of nursing to stroke rehabilitation is not clear. All too often the nurse is seen as the provider of "maintenance care", as compared with the specific therapeutic roles of other members of the team, such as physical therapists and occupational therapists (Gibbon, 1991). This may contribute to the traditional view of the nursing role focusing on "care", but lacks precise delineation of what specifically this "care" encompasses or how it contributes to a stroke survivor's recovery in the rehabilitation context.

Unlike discrete therapy sessions conducted by physical and/or occupational therapists, stroke survivors receive therapeutic rehabilitative care from nurses who, even themselves, are not aware of its therapeutic value (Gibbon, 1991). In fact, Moore (1994a, 1994b) assert that the therapeutic nature of rehabilitation nursing is practised across settings and throughout the whole recovery process. As an illustration, at the initial stage, nursing therapeutics focus on maintaining and improving an individual's physical condition and preventing secondary complications such as stiff joints, pressure sores and pneumonia as much as possible. At the later stage of recovery, the nursing goals are to reduce dependence and to return functional ability to an individual's maximum potential. At this point, the nursing focus also extends to involvement of the stroke survivor's main caregiver. A caring and able family caregiver can be one of the most important positive factors in rehabilitation (American Heart Association, 1998). Health education and coaching are particularly important. Such interventions help stroke survivors and their family caregivers know what to expect; the day-to-day practical skills in self-care and how to handle problems that may arise after the person is discharged from the hospital. All these nursing interventions contribute to the ultimate goals of rehabilitation in helping stroke survivors adapt to life after stroke, attaining the highest possible level of functioning and maintaining an optimal level of well-being. The therapeutic values of nursing include not only what nurses actually are doing to help the stroke survivors recover, but also the ways in which these actions affect the recovery process. To achieve this, a new concept of care model for stroke rehabilitation needs to be considered.

A new concept of care model for integrating social support in nursing stroke survivors

Health care professionals are traditionally socialised in the medical model where professional-led approaches have been emphasised. This model inherits obstacles to the breakthrough of stroke rehabilitation. First is the asymmetrical professional-patient relationship. A stroke survivor is seen as the victim of cerebrovascular disease. He/she must comply with the experts' (doctors, nurses and therapists) treatment for the malfunctioning of his/her body parts. This approach fosters recipient dependence and reliance on professionals, particularly the doctors. Second is the emphasis on curative care. The traditional medical model is pre-occupied with cure of disease rather than promotion of health and well-being. If the medical model is adopted in service evaluation on stroke rehabilitation, the contribution to reducing mortality and supporting life is relatively easy to measure and is highly valued. The contribution of rehabilitation is, on the other hand, less certain.

It may be time for the stroke rehabilitation team to shift their focus from the medical model to a health-oriented model of care. Stroke rehabilitation should be reconsidered in the health domain emphasising health promotion instead of disease cure. According to the World Health Organization, health promotion includes not only nutrition, physical fitness and healthy life-style, but also social support (cited in Boyle, 1989). In fact, the World Health Organization (1984) listed "strengthening of social networks and social supports" as a health promotion strategy. This concept is particularly important for health professionals working in the field of rehabilitation. Augmenting stroke survivors' needs with the supportive resources available in the community is consistant with the current rehabilitation policy aiming for community-based approach and integrating people with disabilities into our society.

Among health professionals, it would seem that nurses are in an excellent position to advance their practice and research in social support, as nurses are working by the patient's side and have closer and more frequent contact with clients and their families. Nurses can use the accessibility of social network members to enhance the supportive resources available. Besides, chronic and disabling illnesses such as stroke have a bi-directional impact on the support network by depleting social support and resources. In that case, health professionals are called upon to provide a new or "created" network to replace or supplement the insufficiency of an individual's existing natural network during the period of stress and transition (Norbeck, 1988). More recently, the therapeutic nature of nursing in a social support aspect has received attention and the importance of establishing the appropriate organisational framework is emphasised (Wright, 1991).

1.2.5 Summary

To summarise, the cost of stroke includes the tangible and intangible costs attributable to disability, discomfort and suffering. The tangible cost of stroke includes the financial cost of an episode of illness, the number of days in hospital, and the days of work lost, but it can also include the financial burden and social effects on the family. The recovery process for most stroke survivors is long. Hence, hospital care is just the first chapter in stroke care. Rehabilitation professionals and policy makers should consider and plan for the post-hospitalisation phase of care.

Our knowledge is scant as to what factors are the most important determinants for the recovery, and perceived well-being after stroke. Traditionally, researchers concentrated on the search for the magic bullet, the pharmacological agent, different treatment patterns to limit cerebral damage or accelerate recovery. This quest has been generally disappointing. There is little doubt that nursing is valued throughout the process of stroke recovery but the specific contribution that nurses make is difficult to measure. It is now time for nurse researchers to look for other areas of endeavour, which might yield more fruitful results.

1.3 Aim and objectives of study

This study aims to present a more comprehensive view on the stroke survivors' perceived well-being after the stroke and to explore whether social support plays a role in the stroke survivors' perceived well-being in the first six months after stroke. These aims are expressed by the following objectives:

1.3.1 To explore the perceived well-being of stroke survivors immediately after the acute phase of stroke and six months later.

1.3.2 To investigate the change in perceived well-being of stroke survivors in the first six months following stroke.

1.3.3 To investigate the role of social support in the perceived well-being of stroke survivors.

1.4 Research questions

1.4.1 How do the stroke survivors perceive their state of well-being (functional status, emotional status and life satisfaction) immediately after the acute phase of the stroke and six months later?

1.4.2 Are there any significant changes in the stroke survivors' perceived well-being (functional status, emotional status and life satisfaction) in the first six months after the stroke?

1.4.3 To what extent is social support available to the stroke survivors in the first six months following the stroke?

1.4.4 Is there any relationship between social support and the stroke survivors' perceived well-being in respect to functional status, emotional status and life satisfaction?

1.4.5 What is/are the factor(s) that predict the stroke survivors' perceived well-being in the aspects of functional status, emotional status and life satisfaction in the first six months following the stroke?

1.5 Hypothesis

From the research questions, two hypotheses are formulated:

1.5.1 There is significant difference between the stroke survivors' perceived well-being in the aspects of functional status, emotional status and life satisfaction immediately after the acute phase of the stroke and six months later.

1.5.2 There is a relationship between social support and the stroke survivors' perceived well-being in the aspects of functional status emotional status and life satisfaction.

1.6 Limitation of the study

The findings of the study are limited to interpretation within the selected stroke population in Hong Kong. Generalisation of the findings should be cautious because of the following factors:

1.6.1 The exclusion of aphasic or dysphasic stroke survivors is recognised as a limitation to the representativeness of the sample. The exclusion of subjects who lack functional speech may explain the absence of a relationship between left hemisphere lesion and depression. In addition, people suffering from aphasia may experience a further decrease in social support due to their diminished ability to communicate. Hence, a non-verbal, behavioural assessment measure needs to be developed for use in future study.

1.6.2 The focus of this study is social support and its relationship to stroke recovery. Personal resources such as coping strategies, self-esteem, social and problem-solving skills are not examined.

1.6.3 The present study attempts to explore stroke recovery in a more comprehensive view relevant to nursing. However, there is no general agreement on the full meaning of "comprehensive" in the rehabilitation context. Therefore, the researcher has adopted the World Health Organization's definition of health as a framework. Other forms of recovery, such as motor power and strength, range of movement and balance, are not included.

1.6.4 The findings of the study are limited to the selected stroke population in Hong Kong. The generalisation of the findings to other stroke population is not appropriate. Convenience sampling methods may have affected the representatives of the subjects in the target population. However, findings from the study indicate directions for care in rehabilitation settings and may help to improve pre-discharge planning and community support for stroke survivors.

1.6.5 The findings of this study relate to the first six months after the acute phase of stroke. The period of six months compared to the long process of stroke recovery is relatively short. As stroke recovery progresses or regresses beyond this point, findings of this study may not capture the full range of possible social support patterns and of characteristics of stroke survivors. Hence, extending the findings beyond this period is not warranted without further evidence.

1.7 Organisation of thesis

The background, aim and objectives of the present study have been explained in this chapter. Remaining parts of the thesis are organised according to the following structure:

The relevant literature in the area of stroke and social support will be reviewed in Chapter Two to identify theoretical constructs and findings from previous studies. The conceptual framework for the study will be described in Chapter Three. Study method will be discussed in Chapter Four where the operational definition and measurement of key variables, sampling and data collection as well as data analysis methods will be explained. Chapter Five describes the pilot study, its findings and its implications for the main study. The Phase I and Phase II results of the main study are reported in Chapter Six and Chapter Seven respectively. Divergence and convergence of findings in the study are discussed in Chapter Eight based on the research questions in the context of stroke rehabilitation nursing in Hong Kong. Chapter Nine presents the implications and recommendations for rehabilitation nursing practice and future studies on stroke. This thesis will be completed with some concluding remarks.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

It is agreed that apart from functional disability, stroke produces psychosocial difficulties. The context of these problems is complex, demanding that researchers and practitioners explore stroke recovery in a more comprehensive approach. Hence, recent studies on stroke have undergone an important change in focus. In addition to incidence, prevalence, and survival, many researchers begin following stroke survivors over time and monitor neurological and functional recovery as well as psychological adaptation. Social aspects of living such as vocational status, social functioning and life satisfaction are also recognised as important indicators of stroke recovery (Cifu and Lorish, 1994; Whisnant, 1994; Bronstein, 1991; Ebrahim, 1990).

In addition to the aspects of stroke recovery, the search for factors affecting successful adaptation after stroke has gained more and more attention in the past decade. White, Richter and Fry (1992) tested a theoretical model of psychosocial adaptation to chronic illness. Their findings suggested a number of factors that may alter the relationship between stress and recovery outcome. Apart from intrinsic factors such as genetic endowment, personality, coping ability, value and attitude towards health and illness, extrinsic factors such as social environment and social support also play an important role in the recovery process. As social resources are relatively accessible, social support has been utilised in promoting adaptation to illnesses, particularly chronic and incapacitating illnesses (Glass and Maddox, 1992; Friedland and McColl, 1992; Glass, Matchar, Belyea and Feussner, 1993; McColl and Friedland, 1995; Mok-Suen, 1998). More recently, research interest in social support has addressed the stroke population. Findings suggested that social support clearly had a role in stroke recovery. Specifically, the enlistment of family support for stroke survivors may significantly modify their ultimate outcome throughout the long process of stroke recovery (Brandstater and Basmajian, 1987).

This chapter is organised around two major themes of this study. First, stroke recovery will be reviewed in the health-oriented approach. In this context, the physical and psychosocial effects of stroke as well as stroke recovery in a more holistic perspective are studied. Second, social support will be reviewed in the context of adaptation to chronic illnesses in terms of its conceptualization, mechanism and role on health and well-being.

2.2. Mechanisms and effects of stroke

2.2.1. Mechanisms of stroke

Stroke is a clinical syndrome resulting from a focal disturbance of cerebral function of presumed vascular origin, sudden or rapid in onset, which persist for more than 24 hours with structural brain damage (Leung, 1995). The types of stroke can be divided into two distinct categories: Haemorrhagic and ischaemic. Haemorrhagic stroke results from either primary intracerebral hemorrhage or subarachnoid haemorrhage. The causes of intracerebral haemorrhage include extravasation of blood from the vessels into the brain or alterations in the normal clotting mechanisms within the blood. Extravasation occurs most commonly in hypertensive patients, who have damage to the small cerebral arterioles which allows blood to seep out of the vessels to the brain parenchyma. Previous studies demonstrate that more than 50% of stroke victims have a history of hypertension or left ventricular hypertrophy (Noll and Roth, 1994; Fuh, Wang, Larson and Liu, 1996; Kong, 1997 (unpublished data). Subarachnoid haemorrhage occurs with a sudden release of arterial blood into the subarachnoid space around the brain. Several diseases known to be associated with subarachnoid haemorrhage include berry aneurysms located on the arteries at the base of the brain and arterio-venous malformation (Wilkinson, 1992). With subarachnoid haemorrhage, in addition to blood escaping to the subarachnoid space, there can also be vasospasm of the cerebral vasculature leading to tissue ischaemia. The goals in managing haemorrahgic stroke are to minimise the amount of initial bleeding, reduce intracranial pressure and maintain perfusion to viable brain cells.

Ischaemic stroke occurs when the blood supply to the brain tissue is partially or totally occluded. Ischaemic stroke can result from embolism from the heart, aorta, carotid or vertebral vessels interrupting or obstructing blood flow to the distal portion of the cerebral vessels. Another cause of ischemic stroke is local thrombus formation in the artery at the site of local atheroma, leading to ischaemia in the area of the brain tissue supplied by the occluded artery. Thrombi usually form in arteries damaged by atherosclerosis that causes endothelial damage within the vessel lining. Most often thrombotic stroke is preceded by a transient ischemic attack (T.I.A.), also called "mini-stroke" (American Heart Association, 1998). Recovery from thrombolytic stroke depends on rapid lysis of the occluding substance (Kay, et al., 1995). Persistent neurological deficit will result when the ischemic brain cells lose their vitality.

2.2.2. Effects of stroke

Stroke is generally regarded as a tragedy. The effects of stroke have been extensively described in many textbooks. Stroke syndrome differs according to the pathological processes and the location of cerebral blood vessels affected. Although stroke survivors may look fairly similar to an untutored eye, to health care professionals, the effects of stroke are unique and vary between individuals. The uniqueness refers to a variety of clinical manifestations that depend not only on the aetiology, side and location of neurological insults, but also on an individual's previous health status and physical abilities, socioeconomical situation, emotional response to stroke and the experience of post-stroke complications (Woo, Yuen, Kay and Nicholls, 1992). Stroke survivors have to face a variety of physical, emotional and social effects that challenge their overall sense of well-being (Bronstein, 1991; Tuomilehto, et al., 1995).

Physical effects

Above all, the classic image of stroke is the loss of function that may be noticed by the stroke victims or is apparent on physical examination. As stroke is caused by disruption in the cerebrovasculature, the resultant neurological impairment entirely depends on the area of brain tissue involved in the pathological process. As an illustration, ischaemic and haemorrhagic events affecting larger arteries lead to more devastating deficits, which can be contralateral or ipsilateral depending on whether motor or sensory pathways are involved and whether the lesion occurs above or below the medulla (Ebrahim, 1990; American Health Association, 1998).

Common features of neurological impairments and disability include but are not limited to immobility, impaired sensation, dysphasia/aphasia, dysphagia, homonymous hemianopia, neglect of affected side, cognitive impairment and disfigurement (Doolittle, 1988). Among all effects, paralysis or paresis on the contralateral side is common (American Heart Association, 1998). However, not all strokes are the same. Some generalisations about right versus left stroke are identified. Left stroke may be accompanied by right hemiplegia, aphasia and other communications impairments, but the ability to learn may be retrained. Right stroke is often associated with perceptual-motor problems, left-sided neglect and loss of visual-spatial memory. Survivors with a right stroke may show poor insight, judgement and impulsive behaviour. In some situations, due to partial occlusion of the basilar artery, the 'locked-in' syndrome occurs. This means that despite intact consciousness and sensation, stroke survivors are left with complete paralysis except for eye movement (Barker, 1994).

The extent of disability may be exacerbated by complications such as painful hemiplegic shoulder, spasticity, contracture, pneumonia, constipation, falls and fracture. Grief and depression are not uncommon, for what has happened was sudden and awful. The life of the stroke survivor will not be the same again.

Psychological effects

Compared to the extensive knowledge of physical impacts, psychological effects after stroke have long suffered from inadequate attention. One of the reasons may be attributed to the overwhelming effects of changes in physical functioning. This leads to a general misconception that grief following stroke is natural and will disappear as time passes. Frustration, sense of grief and depressive mood at the early stage of stroke recovery are accepted as "normal". Stroke survivors are labeled as "apathetic" or "lazy" if they are found not to be motivated during rehabilitation activities. Those who express their frustration are often labeled "difficult". The psychological consequences of stroke, particularly post-stroke depression, are often underestimated by health care professionals (Doolittle, 1988; Bronstein, 1991; Fuh, Liu, Wang, Liu and Wang, 1997).

Alternatively, depressive mood after stroke has been a concern of neurobehavioural scientists. More recently, post-stroke depression has gained more attention from social scientists and health care professionals. Without timely identification and treatment of depressed stroke survivors, successful rehabilitation may be delayed and human suffering is prolonged (Bronstein, 1991).

The issue of lesion location and mood disorders continues to be debated in neurobehavioural sciences. Some findings indicate that location of lesions has some correlation with mood disorders. A study on predicting stroke rehabilitation outcome indicated that survivors with left frontal lesions exhibited a greater degree of depression (Novack, Graham and Satterfield, 1987). Studies from Robinson, Bolduc and Price (1987) also indicated that survivors with left hemisphere lesions were significantly more depressed than those with right hemisphere or brain stem stroke. Depression could be sustained in the majority of cases for more than six months after the onset of stroke (House, Dennis, Warlow, Hawton and Molyneux, 1990; Fuh, Liu, Wang, Liu and Wang, 1997).

Although some researchers provided findings that laterality of stroke insult had influence on psychological reaction; little definite evidence exists to support that argument. Sandi, Cifu and Noll (1994) showed that emotional problems were not solely determined by specific lesion locality. In fact, the literature on behaviour in stroke demonstrates that emotional problems after stroke have a physical and/or psychological basis. As an illustration, when an individual survives the acute stage of stroke and returns home or to the pre-morbid setting, he/she often faces one difficult task after another, with tasks that were once automatic. With almost every personal need, the individual is faced with deficit and inability. The former lifestyle in a comfortable, safe setting no longer exists. For an individual who enters into an extended care facility, apart from the devastating effect on physical function after a stroke, he/she has to deal with personal and cultural meanings of institutionalisation. Stroke survivors may have no choice but to sink deep into dependency on others

(Dolittle, 1998). The inability to attend to toilet needs and to feed or bathe oneself is not enthusiastically received in our society. In addition to the physical impairment, social and environmental barriers further exaggerate the impact of physical disability. Stroke survivors experience severe personal frustration and disappointment. This may also contribute to post-stroke depression (Wade, Legh-Smith and Hewer, 1987; Bronstein, 1991; Ebrahim, 1990).

Social effects

The sudden, devastating effects of stroke often undermine an individual's status and identity as well as reduce the capacity to perform usual roles. In particular, for those who lose their job and/or encounter financial difficulties, lives after a stroke are greatly impaired. The loss of prestige and power may have adverse effects on self-esteem and self-confidence (Brandstater and Basmajian, 1987).

In addition, Jongbloed, Stanton and Fousek's (1993) findings further highlight that not only the stroke survivor has to deal with the sudden change, the entire family is fundamentally affected. Current policy initiatives towards de-institutionalisation and trends towards shorter length of hospital stay suggest that many stroke survivors with residual disability depend on help from their family members once they return home (Brereton, 1999). Taking care of the stroke survivor at home can cause considerable burden and strain to the family (Hodgson, Wood and Langton-Hewer, 1996). Evans, et al. (1992) examined role change in the family after a stroke. Findings indicated that role responsibility increased with regard to decision making about a range of issues and the involvement of family members, especially the spouse, in social activities. Marital disharmony was identified in some sampled couples. Children may be unable to take on the responsibility. This problem has increased with a greater mobility of family and a diminishing traditional family concept (Chang and Mackenzie, 1998). Indeed, to date, the role of the family caregivers and family functioning have not been directly identified as predictors of stroke outcome. However, Evan et al. (1992) suggested that poorly functioning families would potentially be unable to comply with treatment regimen. If timely support to the caregivers is not available, stroke survivors, similar to those with other chronic neurological illnesses, may be rejected or deserted by the family. This creates an indirect social effect of a stroke.

Unrealistic hopes and attempts to regain pre-stroke status in terms of independence and employment may create greater frustration to stroke survivors. Alternatively, some stroke survivors may become excessively dependent and helpless. Clients at these two extremes are predisposed to develop more prolonged levels of withdrawal and social disability following a stroke.

2.3 Stroke recovery

Increase in knowledge about the aetiologies and treatments for stroke has paralleled the development of research on assessing and predicting stroke recovery. However, given the complexity of the effects of stroke, evaluation of stroke recovery has many problems that will be discussed according to two aspects: the recovery process and the recovery outcome.

2.3.1. The process of stroke recovery

Stroke recovery can be classified into two categories: Intrinsic recovery (also called spontaneous or natural recovery) and extrinsic recovery (also called functional recovery through intervention/rehabilitation). There is a general belief that rehabilitation is effective. However, at present, one cannot determine whether a good recovery is the result of a specific intervention or the natural recovery process. In intrinsic recovery, time is an important factor. Stroke victims will either die or recover to some extent over time. The natural history of recovery provides fundamental information that allows comparisons between groups in clinical trials. Nonetheless, review of relevant literature showed that some evaluative studies with pre- and post- comparison design have not considered the inclusion of a concurrent control group. This can explain why many interventions/treatments appear to be effective, because allowance is not made for spontaneous recovery.

Investigation of the time course of recovery was conducted by many researchers in the past ten years. Common findings indicate that neurological and functional recovery is strongly related to initial stroke severity. Although neurological recovery is achieved faster than functional recovery, the two types of recovery could best be achieved within the first six months after a stroke (Andrews, Brocklehurst, Richards and Laycock, 1981; Skilbeck, Wade, Hewer and Wood, 1983; Kotila, Waltimo, Niemi, Laaksonen and Lempinen, 1984; Reding and Potes, 1988; Smith, 1990; and Duncan et al., 1994). This time course of recovery was further supported by The Copenhagen Study conducted by Jorgensen et al. (1995). The Copenhagen Study was prospective in design and followed a large (N=1197) community-based sample of stroke survivors. Their findings showed that the best neurological outcome was reached within 11 weeks from stroke onset and the best functional outcome was reached within 13 weeks from stroke onset. After this time, no significant changes were observed (Jorgensen et al., 1995). Such findings provide an important guideline for future researchers to consider in terms of the duration of a prospective study into the course of recovery.

2.3.2. The recovery outcome and its predictors

Due to the overwhelming effects on cerebral function, early stroke recovery outcome indicators mainly focus on survival and neurological impairments. Pharmacological agents that can improve survival and reduce the extent of impairments were regarded as magic bullets for stroke management. Nevertheless, these outcome indicators cannot indicate the effectiveness of rehabilitation effort. In recent decades, the focus of stroke recovery outcome indicators was extended to a more functional perspective, to investigate the disability due to neurological impairments and the stroke survivors' ability to perform. As performance in mobility can be observed, functional outcome indicators are considered to be measurable and scientifically objective. In addition, scientific inquiry on predictors of functional recovery after a stroke also gained more attention in recent functional outcome studies. Predictors of stroke recovery can be grouped under two major categories and are discussed as follows:

Clinical factors

Clinical factors, such as pre-morbid health status, co-morbidity, aetiology, pathological process, side and location of cerebral insult, as well as the extent of neurological impairment have a direct effect on stroke recovery. There have been studies contrasting the predicting effect on stroke recovery of the right hemisphere damage with that of the left hemisphere, with the focus on unilateral involvement of the brain. Apart from contralateral effects on mobility and sensation, it is generally well understood that damage to the left hemisphere affects language and time concepts, whereas damage in the right hemisphere affects performance, spatial orientation, anosognosia and neglect (Brandstater and Basmajian, 1987). However, when brain damage is deep and involves the internal capsule, researchers or rehabilitation professionals should also consider the bilateral effect. Hence, one should be cautious in using terminology. The "involved" limbs may actually refer to the "more involved" limbs. Hence, not only the side, but also the site and location of stroke as well as the extent and severity of initial neurological impairments need to be addressed in examining the recovery potential.

Certain neurological deficits predict poor recovery. Survivors with motor impairment, such as excessive flaccidity and spasticity for a prolonged period, often have poor mobility and self care. Sensory impairment on the involved side has poor effect on survivors' re-learning ability. The American Heart Association (1998) reports that those with more neurosensory impairment perform worse in the self-care index and have poor recovery potential. For instance, the functional loss of visual field has an adverse effect on rehabilitation training and prolongs therapy. Visual field defects have an adverse effect on both learning self-care and mobility. Persistent incontinence is generally considered a poor predictive sign for stroke recovery. Apart from organic brain or lower urinary tract involvement, inability to ambulate was once considered as one of the causes for functional urinary incontinence. In addition, when examining predictors of stroke recovery, co-existing illnesses must be considered. Co-existing illnesses commonly related to stroke include hypertension, hyperlipidaemia, cardiac decompensation, atherosclerosis and diabetes mellitus.

Demographic factors

Other than clinical factors, demographic factors are commonly studied by epidemiologists to detect their predictive value on stroke outcome. Most of these studies used survival, disability, length of hospital stay and discharge disposition as dependent variables. Independent variables included a large variety of treatment and demographic variables. Brodie, Holm and Tomlin (1994) examined the relationship of demographic, diagnostic and occupational therapy antecedents to stroke outcomes. Results showed that among demographic variables, premorbid living situation, marital status and age made significant contributions to the prediction of stroke discharge disposition. Similar findings were also found in studies conducted by Abu-Teid, Choi, Hsu and Maini, (1978); Woo, Ho, Lau and Yuen, (1994); Hakim and Bakneit (1998). Hakim and Bakneit (1998) suggested that younger stroke survivors show better recovery than their older counterparts. This finding supports the conclusion that rehabilitation potential decreases with increasing age.

The role of gender in predicting stroke recovery also draws researchers' interest. Almost all studies indicate that the sex of stroke survivors has no association with stroke recovery (Abu-Teid, Choi, Hsu and Maini, 1978; Henley, Pettit, Todd-Pokropek and Tupper, 1985; Woo, Ho, Lau and Yuen, 1994; Tomlin, 1994;).

Site of residence after a stroke is thought to play a definite role in recovery prognosis. Earlier studies found that stroke survivors living in nursing homes or long-term care facilities had minimal, if any, recovery prognosis (Lehman et al. 1975; Gordon, Drenth, Jarvis, Johnson and Wright, 1977). However, subsequent studies report different findings. Stroke recovery is not so much related to the place of residence but rather to the extent of impairment, the availability of appropriate treatment and rehabilitation services (Abu-Teid et al., 1978; Loo, 1993; Reutter and Rentsch, 1993; Woo et al., 1992). To avoid prejudice against nursing home subjects, researchers should be alert to avoid sampling bias as well as confounding the effect of place of residence and other variables. As an illustration, if the subject is in a nursing home because of social reasons rather than medical reasons, place of residence might play a greater role because family support is suggested as being one of the significant factors in stroke recovery.

A major criticism of previous community-based predictive studies refers to the cross-sectional design instead of looking at long-term outcomes. Cross-sectional design limits the examination of improvement that was made from the intrinsic recovery or during the intensive rehabilitation period. Results of these studies have varied, and thereby caused some controversy or confusion regarding the importance of various demographic factors and their influence on stroke recovery. Consequently, each of these specific demographic factors warrants careful consideration.

To summarise, the review of medical outcome studies on stroke in the past decades noted that there was an overemphasis on functional recovery (Wade and Langton-Hewer, 1987; Adunsky, Hershkowitz, Rabbi, Asher-Sivron and Ohry, 1992; Dekker, Arendzen and Eisma, 1995; Smith and Clark, 1995; Chang and Mackenzie, 1998), with minimal attention given to the psychological response towards loss of functions, as well as social consequence experienced by the stroke survivors.

Such limitations in medical outcome studies can be attributed to the disease-oriented concept of stroke recovery: A stroke results in a measurable loss of physical function. However, the human perception towards disabling sequelae is often neglected. Gompertz, Pound and Ebrahim (1994) interviewed forty stroke survivors ten months after a stroke. Their responses asserted that stroke is a personal disaster. Stroke survivors were faced with loss – the loss of vitality, valued role, integrative capacity and a sense of wholeness about themselves. However, such human perception would not easily have been captured using conventional standardised functional outcome measures. More challenging to health professionals is that such sense of loss does not surface immediately after a stroke, but very often occurs after the individual is discharged from a in-patient rehabilitation programme. In the studies on consequences of stroke, Pound and Gompertz (1998) and Gibbon (1991) pointed out that stroke survivors might initially share their therapists' concerns with functional improvements. As time went by stroke survivors shifted their concerns to a more holistic sense of recovery. However, in the review of stroke outcome studies, it is not surprising to notice that stroke survivors were still evaluated by functional ability years after a stroke, with minimal or virtually no attention given to their psychosocial aspects of recovery (Woo et al., 1992). To have a more comprehensive understanding about different aspects of recovery, nurse researchers need to adopt a health-oriented approach in evaluating stroke recovery. Factors facilitating stroke survivors' holistic sense of well-being could then be identified. With this knowledge, nursing intervention for stroke rehabilitation can be planned in an appropriate and cost-effective way.

2.4. Health-oriented approach to assess stroke recovery: a holistic sense of well-being

The ultimate aims of a variety of care and treatments are to reduce a patient's suffering and improve his/her holistic sense of well-being. Surprisingly, the subjective sense of well-being has not commonly been used as an outcome indicator in medical outcome studies. Even where it is used, the term is seldom defined. Therefore, research studies on subjective well-being are often inconsistent in their terminology and concepts (Ebrahim, 1990).

The contemporary concept of health proposed by the World Health Organization can provide a framework for understanding the holistic sense of well-being. Health is a state of physical, mental and social well-being, not merely the absence of symptom or infirmity. Currently, many terms are intended to reflect the holistic sense of well-being. Among these, quality of life has been used extensively. Similar to the concept of health, this has diverse meanings. Quality of life is an elusive concept, which is difficult to define in precise terms (Engstrom and Nordeson, 1995). In the global perspective, quality of life implies "good life" encompassing a wide range of indicators including health, wealth, housing, education, employment, environmental issues as well as autonomy and democracy. In the health-related perspective, Cheater (1998) suggests that quality of life represents a general sense of well-being incorporating biological factors such as physical function and freedom from symptoms as well as non-biological factors such as psychological well-being, socioeconomic status, access to health services and social support.

Engstrom and Nordeson (1995) conducted a qualitative study on 169 neurologically impaired patients, inquiring into their perception of well-being. Most of these patients suffered from progressive neurological diseases such as multiple sclerosis, Parkinson's disease and other neuromuscular disorders with many years' experience of ill health. Some general themes were discerned including: living in a sense of affinity (living with family, emotional ties and friendly solidarity at work), being independent, living on one's own terms as well as feeling that life is meaningful. Other studies also found that biological and non-biological aspects of perceived well-being may be independent of each other. Chronically ill patients may have a better sense of well-being if they experience positive changes in their feelings, such as ability to cope, self-esteem, adjustment and self-concept even when there has been little or no change in their functional status. Similar findings were found in other studies identifying aspects of quality of life from the patients' perspective including independence, respect, happiness, vitality, value of life and spirituality (Bertero and EK, 1993; Meeberg, 1993; Dale, 1995; Chang and Mackenzie, 1998).

2.4.1. Problems in measuring quality of life

Literature showed diverse approaches in the assessing of a health-related sense of well-being. Among these, quality of life seemed to be studied extensively. It is generally agreed that quality of life is a personal and individual matter. In fact, it is not only subjective but also context specific. Therefore, quality of life is fluid, changing with time, place and circumstance. This is particular true for those who suffer from chronic ill health. Patients' perception and feelings towards their condition may change as the disease progresses or recovers. Measuring quality of life in stroke survivors should be patient-centred and longitudinal in design, yet specific enough to reveal the progress of recovery that makes reference to the evaluation of intervention and identification of care needs.

In the relevant literature, there are more than 100 heath-related quality of life (QoL) measures used in a variety of clinical conditions, particular in chronic illnesses (For example, McDowell and Newell, 1996; Bowling, 1995; Bowling, 1991; Fallowfield, 1990). Commonly known QoL measures can be categorised into three main streams: (1) Generic measures, (2) Disease-specific measures and (3) Scale batteries. Researchers need to consider which type of measure is required, depending on the particular aims of the study.

Each stream has its strengths and weaknesses.

(1) Generic measures:

Commonly used generic QoL measures for stroke include the Nottingham Health Profile (NHP) (Hunt, McEwen and McKenny, 1985); the Sickness Impact Profile (SIP) (Bergner, 1976), the SF-36 (Cheater, 1998) and General Health Questionnaire (Goldberg and Blackwell, 1970). These measures are multidimensional profiles or indices, combining measurements of physical function, psychological and social dimensions of health in one instrument. These instruments produce a set of scores on each dimension and a composite score indicating the overall QoL.

Generic measures are suitable for a wide variety of conditions. Therefore, comparing disease groups and detecting the relative effects of disease and treatment on different life domains are possible. In terms of their application to the study of stroke outcome, generic measures are good for producing a global picture on stroke survivors' perceived quality of life. However, generic measures carry limitations. Particularly important is their non-specific nature, which may mask a factor that may be of major importance to stroke survivors. Therefore, it may not be specific enough to inform and guide interventions (Cheater, 1998).

(2) Disease-specific quality of life measures

By contrast, disease-specific quality of life measures are more sensitive and particularly relevant to a specific population of patients. They have their strength in their sensitivity to detect small but clinically significant changes in health status and severity of illness. Their limitation is mainly their narrow focus of measurement, which can omit assessment of the impact of illness upon wider aspects of patients' lives. Also, they are too specific to allow cross-disease comparisons. However, stroke specific QoL measures are not widely used compared with generic measures. The relevant literature showed that stroke-specific QoL measures are limited. The Frenchay Activities Index for stroke patients developed by Wade, Legh-Smith and Hewer (1985) consists of 15 activities, half of which are "higher-order" activities of daily living. Items include doing household tasks, walking outdoors and gardening. Social outings such as shopping, using public transport and work are also included. Again, King (1996) examined quality of life after stroke with the Ferrans and Powers Quality of Life Index (QLI) - Stroke version. The original QLI measures (including 4 subscales: health and functioning, socioeconomic, psychological-spiritual, and family) were modified by the addition of communication, self-care and mobility items. Apart from the QoL measures, King's study also included other more clinically specific measures such as the Functional Independence Measure for ADL assessment; Centre of Epidemiology Study - Depression for assessing depression. The domains in the quality of life measures are overlapping with other measures.

In addition to the disease-specific measures, there are domain-specific measures which assess constructs such as self-esteem, adjustment, locus of control, role functioning and self-concepts. Chang and Mackenzie (1998) followed 152 stroke patients for the first three months to assess the state of self-esteem and its relationship with functional independence. The psychosocial domain in stroke recovery was highlighted. However, as previously mentioned, quality of life is very individual and context specific. Self-esteem may be of major concern for one stroke survivor but not necessarily important for another. Even for the same person, concern for self-esteem may not be present at the early stage of recovery. This is because domain of interest varies according to how the condition and its treatment affect the stroke survivors. Using Chang and Mackenzie's (1998) study as an example, self-esteem is of interest to the researchers. However, the more prominent psychosocial consequence, namely, post-stroke depression was not addressed. Narrow focus on one particular domain can (1) include an in-depth understanding of a particular domain that may be unimportant to the patients or (2) exclude other important domains that are of relevance and importance to patients at different stages of recovery.

(3) Scale batteries

These are an elaboration of disease-specific QoL assessment. A battery of scales for measuring particular dimensions of health is used. As an illustration, quality of life domains can be assessed by a series of specific instruments. The independence in self-care is measured by an activities of daily living scale. The emotional status is measured by a depression or happiness scale. The advantage of using such a series of specific and unidimensional measures allows assessment of each relevant life domain in depth. The findings can specifically inform and prioritise aspects of interventions. Such an approach can also compare with other disease groups of similar nature. However, the disadvantage is the subject burden associated with completing such a battery. Field tests must be arranged to assess the feasibility of application in a particular subject group.

In summary, there is no golden rule to indicate what properties, symptoms or functional limitations are the most important determinants of stroke survivors' quality of life or holistic sense of well-being. Recent stroke outcome trends have suggested a broader sense of well-being where several domains are involved: physical, functional, psychological and social health (de Haan, Aaronson, Limburg, Hewer and Crevel, 1993; Wyller, Holmen, Laake and Laake, 1998). The physical domain includes stroke-related syndromes and post-stroke complications. The functional domain includes independence in activities of daily living and self-care. The psychological domain includes emotional status (especially post-stroke depression), life satisfaction and happiness. The social domain includes the aspects of social contact and interactions as well as the ability to resume the pre-morbid role, social and leisure-time activities. This interpretation of well-being is closely linked to the World Health Organization's definition of health: a state of complete physical, mental and social well-being and not merely the absence of disease or symptoms (Lukkarinen and Hentinen, 1997; WHO, 1984).

The four domains comprising well-being will be discussed in the following paragraphs. The concepts and methodological issues in previous studies will also be discussed. As the terms quality of life and perceived well-being are used interchangeably, in order not to confuse the global and health-related focus on quality of life, the term "well-being" will be used in this thesis.

2.4.2. Functional well-being

One of the commonly recognised rehabilitation outcome indicators is the ultimate functional capacity achieved by survivors. No matter how severe the stroke is, a stroke survivor tends to participate, to some degree, in physical aspects of rehabilitation, as it is a way of attempting to achieve one goal after another. Through physical rehabilitation one could regain functions, which in turn give more independence. Lewinter and Mikkelsen (1995) interviewed 21 stroke survivors investigating their experiences after acute stroke. Their findings suggest that the majority of rehabilitation professionals and stroke survivors concentrate on physical retraining because this is something that they could 'deal with' and for which they can set objectives. For example, how well can the individual balance when sitting, how far can the individual walk and up how many steps the individual walk. Enhancement of levels of function is the essential and intrinsic goal of the stroke rehabilitation programme. Mobility and independence in activities of daily living are widely studied among stroke survivors.

For the purpose of more objective comparison, the measurement of physical independence or disablement is usually compressed into standardised scales. Scales of activities of daily living (ADL scales) have been widely used to assess functional status before, during and following rehabilitation programmes. Wade and Hewer (1987) and Gompertz, Pound and Ebrahim (1994) identified some criteria for measuring functional recovery. It is recognised that a functional assessment instrument should, apart from its reliability and validity, also be relevant to both user and patient, sensitive to clinically relevant changes, simple to administer, and communicable to non-specialists. The relevant literature shows that a number of instruments fit these criteria and are commonly used in stroke outcome studies. For example: the Functional Independence Measures, the Katz index of ADL and the Kenny Self-Care evaluation (Granger, Greer, Liset, Coulombe and O'Brien, 1975; Granger, Sherwood and Greer, 1977; Granger, Dewis, Peters, Sherwood and Barrett, 1979; Granger, Hamilton, Gresham and Kramer, 1989). In general, these ADL scales have been developed to categorise and quantify musculo-skeletal and neurological disability. In practice, ADL scales result in a composite score, which reflects a blend of dimensions of stroke-related disadvantage, namely, impairment, disability and handicap (Wood, 1980). Among a number of activities of daily living scales that fit the criteria, the Barthel Index (BI) has been suggested as a universal standard (Collins, Wade, Davies and Horne, 1988; Gibbon, 1991; Gompertz, Pound and Ebrahim, 1994).

Previous studies found that the Barthel Index (BI) proved to be of functional prognostic value in the study of stroke rehabilitation outcomes (Granger, Greer, Liset, Coulombe and O'Brien, 1975; Granger, Sherwood and Greer, 1977; Granger, Dewis, Peters, Sherwood and Barret, 1979; Wade and Hewer, 1987; Granger, Hamilton, Gresham and Kramer, 1989; Gompertz, Pound and Ebrahim, 1994). It has been of particular value in a large number of studies that have generated normative data for stroke recovery. The frequency of classification of overall independence in activities of daily living in stroke survivors, as determined by the BI, does not differ significantly from frequencies derived by other highly respected functional assessment instruments (Wade and Hewer, 1987; Gompertz, Pound and Ebrahim, 1994).

The Barthel Index (BI) was developed by Mahoney and Barthel in 1965. At present, in Hong Kong, it is the most widely used instrument for assessing independence in activities of daily living. The items of BI form a hierarchical scale that gives a score between zero and twenty in one point increments. The top score of 20 implies independence but not necessarily the ability to live alone. Information about function was recorded for the 24 hours before the assessment from the best possible source (patient, nurse or family).

However, a major criticism of currently used ADL scales, including the BI, points out that these scales measure only essential survival activities, such as continence, feeding and mobilising. Rehabilitation professionals have gradually recognised the limitation of such ADL scales as successful rehabilitation concerns not only mastering of basic activities of daily living skills, but also includes reduction of disability and restoring of an individual's independence to a point at which reliance on the family and community resources becomes minimal (Smith and Clark, 1995).

2.4.3. Functional recovery in the social aspects of well-being

Van Hark and Arenden (1995) commented that the measurement of physical independence by well-recognised standardised scales such as the Barthel Index (BI) or Functional Independence Measure (FIM), is still too superficial to capture the reality that stroke survivors have to face in community living. They argue that these standardised questions are general and out of context and a number of essential activities, which have to be carried out by an individual in community dwelling, are not considered. Smith and Clark (1995), Geraldine and Christina (1997) and Wyller, Sveen, Sodring, Pettersen and Bautz-Holter (1997) also expressed a similar opinion that ADL scales are unable to reflect the social aspects of living. However, the relevant literature reveals that little has been done to observe and describe problems in the activities of daily living that are faced by stroke survivors in resuming social and leisure-time activities.

Extended activities of daily living scales can reflect some of the higher level activities that require increased interaction with the environment, whether household or community (Chong, 1995), for example, cooking, doing household tasks and management of one's own finances. Some aspects of social living such as going outdoors, meeting friends are also included. These are more relevant and appear to be a prerequisite for independent living in the community. Instruments measureing extended ADL include The Rivermead ADL assessment (Whiting and Lincoln, 1980), The Hamrin activity Index (Holbrook and Skilbeck, 1983), The Frenchay Activities index (FAI) (Lincolin and Edmans, 1990; Wade, Legh-Smith and Hewer., 1985) and The Nottingham Extended ADL scale (NIP) (Ebrahim, 1990; Nouri and Lincoln; 1987). Except for the FAI, extended ADL scales categorise items into different domains. However, none of the instruments is developed based on a solid theoretical construct and they do not define extended ADL (Chong, 1995). In terms of the consideration of the patient's perspective, a review of the literature further established that the NIP was the only measure that was developed incorporating the patient's view. A major criticism of extended ADL measures is the question of whether items really reflect a social aspect of living such as an individual's social and leisure-time activities. Moreover, the cross-cultural application is also questioned, because social activities vary in different social economic groups and in different cultures.

The implication for future studies is to have a more relevant assessment of functional recovery in particular, on the social aspect of living, after the individual has been discharged from hospital. Assessment of extended activities of daily living and participation in daily lifestyle activities should be considered and compared with the pre-morbid state, so as to assess the stroke survivor's ability to carry out functional tasks relevant to community dwelling as well as characterise the stroke survivor's ability for social survival. Nevertheless, physical functioning in a community setting and social survival are very much related to the social facilities, resources and other social cultural factors. Measures developed in the West may not be sensitive enough to be used in Hong Kong. Hence, a culturally sensitive measure on the social aspect of living (i.e. social and leisure-time activities) should be considered for use in the Hong Kong Chinese population.

2.4.4. Psychosocial well-being

Apart from neurobehavioural deficits, psychological consequences are associated with other factors such as pre-stroke personality, physical and intellectual impairment, general meaning of the disease to the survivor, self-perception towards stroke disability, the reaction of significant others towards stroke, the response of the stroke survivor's social network, the extend of loss of status and finances as well as social re-integration of the survivor outside the immediate family (Sandin, Cifu and Noll, 1994; Astrom, Asplund and Astrom, 1992; Bronstein, 1991; Silliman, Wagner and Fletcher, 1987).

Although the presence of psychosocial dysfunction has been addressed in the study of stroke recovery, less emphasis has been placed on it. Studies on psychosocial consequences after stroke indicate that no matter how minor the disability is, stroke survivors face a wide range of stress and psychosocial changes, for example, but not limited to, changes in physical function, loss of social and vocational roles, disruption of life styles, threats to self-image and self-esteem as well as uncertain and unpredictable futures (Chang and Mackenzie, 1998; White, Richter and Fry, 1992). When the accumulation of stressful events is great (such as a sudden stroke) and considerable physical, emotional and social readjustment are required, well-being is threatened. Recent studies indicate that psychosocial adjustment is often poor for the stroke survivor. Poor psychosocial adjustment may be manifest in various forms, for example, insomnia, anxiety, somatic complaints, or social withdrawal, but probably its most recognisable form is depression (Bronstein et al., 1986; McColl and Friedland, 1989; Stern and Bachman, 1991; Tuomilento, 1995; Fuh, Liu, Wang, Liu and Wang, 1997).

Post-stroke depression is of great importance with regard to rehabilitation and well-being of stroke survivors. The prevalence of depression after stroke has been estimated to be 14-60% (Wade and Hewer, 1987; Argell and Dehlin, 1989; de Hann, Limburg, Van der Meulen, Jacobs and Aaronson, 1995; Duncan et al., 1997; Fuh, Liu, Wang, Liu, and Wang, 1997; Herrmann, Black, Lawerence, Szekely and Szekely, 1998). As stroke is an unexpected and traumatic event, post-stroke depression is generally thought to be an understandable and perhaps an inevitable psychological reaction. Some even claim that the occurrence and intensity of depression will decrease spontaneously in time. Unfortunately, all these assumptions have led to neglect or delay with therapeutic intervention for depressed stroke survivors. Until recently, the prevalence and magnitude of the depression and the importance of assessing post-stroke depression as one of the elements in stroke recovery have been severely underestimated.

Although losses in the area of functional performance account for depression among stroke survivors, it has become increasingly clear that there is not a simple linear relationship between the two. Compared to orthopaedic patients with the same degree of physical disability, depression is four times more common among stroke survivors (Agrell and Dehlin, 1989). Glass, Matchar, Belyea and Feussner (1993) examined a subsample of fully recovered stroke survivors and found that independence as determined by ADL measures is unrelated to poor psychosocial adjustment. In fact, there is a positive relationship between a good psychosocial outcome and the ability to attend leisure and socialising activities as well as a return to pre-morbid role and employment status. Since depression after stroke is common and early identification and treatment can prevent further devastating consequences and facilitate rehabilitation, depression must be included in any stroke recovery assessment, to identify characteristics of high-risk groups and make early intervention possible.

In parallel with the functional outcome index, neurobehavioural studies on stroke population tend to put a major focus on post-stroke depression. For the purpose of more objective comparisons, the measurement of depression is usually compressed into standardised scales. Several popular self-reported depression scales are reviewed for application in the present study. The most commonly used depression scales in a post-stroke population include Beck Depression Inventory (BDI), Geriatric Depression Scale (GDS) and Center for Epidemiology Scale – Depression (CES-D). All of these scales have well-validated Chinese versions and have been used in cross-cultural studies as well as in Hong Kong.

The BDI consists of 21 statements. The answer format is presented as a series of ordered statements. Respondents are asked to choose the statement which best describes their current situation. The construction of the scale is based upon the theory of Cognitive Triad and is composed of three basic cognitive aspect of depression, namely: negative expectations of the present environment, negative view of self and a negative expectation of the future (Beck, 1969, 1970). BDI is one of the most commonly used scales for examining depression (using cut-off scores of 13 for screening and 21 for diagnostic purposes). The strengths of the BDI are the reliability and validity of the scale. Also, questions are short and easy to answer. A major criticism of BDI concerns its use in specific client groups, for example, inflated scores are noted among elderly subjects on the somatic content of the scale (Chan, Yu and Tsui, 1997). In addition, inter-personal items that are important aspects of emotion cannot be reflected in the scale.

The Geriatric Depression Scale (GDS) has been widely adopted as a self-report measure for depression in old age. The GDS contains 30 items in the full version. It is reported to have good reliability (Cronbach alpha ranges from 0.85-0.93) and validity (concurrent validity range from 0.62-0.94). A specific strength of this scale is its relatively low weighting for the somatic symptoms that are frequently reported in elderly and stroke survivors. Other advantages include its short and easy to answer format (yes/no). A major limitation of GDS for use in stroke survivors is its limited use in elderly groups. However, a recent figure indicated that the incidence of stroke in the young is increasing (Hospital Authority, 1997, 1998; Kong, 1997 (unpublished data). Even for the elderly group, the ethical applicability of GDS in the stroke population is questioned. In particular, some statements require stroke survivors, who are confronted with body disfigurement and sudden loss of functions to judge whether it is good to survive.

The Center of Epidemiology-Depression Scale (CES-D) is a 20-item scale designed to identify an individual's current depressive mood (the affective component of depression) and to measure its severity. Respondents are asked how often they have experienced the identified feelings in the past 7 days. The 20 items are graded into a 4 point Likert scale. The design itself was originally for screening purpose. It is also reported to have high internal consistency (alpha coefficient ranges from 0.76-0.92). Validity, when compared to other scales as well as with clinician's rating, ranges between 0.44-0.89 (Chan, Yu and Tsui, 1997). The advantages of CES-D include its cross-cultural applicability and its validated use in the stroke population. However. researchers should be cautious, particularly as appropriate cut-off scores for clinical screening have yet to be validated. This leaves an open question as to the validity of cut-off scores across different cultures (Weissman, Prusoff and Newberry, 1975; Roberts and Vernon, 1983; Ying, 1988 and Katz et al., 1996) as well as between community and clinical samples. Another reason to exercise caution in the use of CES-D is that understanding of the items may be a problem. Radloff (1977) revealed that there was a very small but consistent correlation between the CES-D score and the interviewer ratings of the understanding of the questions, independent of education of the respondent.

The relationship between physical and social conditions surrounding stroke survivors adds to the complexity of assessing the prominence and role of depression. Some implications for future studies are identified. First, when choosing the depression scale to be used with stroke survivors, the set of criteria should consider not only the psychometric properties, validity and discriminatory ability, but also its suitability for use in the post-stroke population. This includes the answer format and length of the scale, the construction of the scale as well as cultural sensitivity. These should all be borne in mind. As an illustration, the limited attention span of stroke survivors, a multiple choice answering format and lengthy scale may create confusion in the respondents. Scales that focus on somatic content may be misinterpretated where negative response may be due to functional impairments rather then depression.

Second, previous researchers tend to rely heavily on the use of self-administered methods in data collection to judge the presence and severity of depression. Such an approach carries both clinical and research limitations. Clinical signs of an emotional component are not always reinforced by reliable evidence and individuals with brain damage (such as a stroke) may not provide valid self-administered data (Whitney, Burns, Frederic and Lowery, 1994). Also, stroke survivors may have difficulty in participating in the study because of motor or sensory impairment.

Third, researchers should also be aware of the limitations of other post-stroke depression studies including: small sample size, poor selection criteria, lack of attention to confounding variables, exclusion of aphasic or cognitively impaired stroke survivors as well as the unjustified use of conventional cut-off scores for the stroke population.

2.4.5 Factors affecting the perceived well-being of stroke survivors

The contemporary view on stroke recovery is moving towards a holistic approach. Stroke recovery refers not only to the return of physical function, but also the psychosocial adaptation towards life after stroke. Stroke survivors' perceived well-being in functional, emotional and social perspectives is considered an important recovery indicator. If evaluation of stroke recovery is shifted from a disease-oriented model towards a health-oriented model, the traditional outcome predictors for stroke recovery may only reflect part of the picture. Other factors such as coping styles and social aspects that contribute to the psychosocial adaptation towards illness may also need to be considered in the study of stroke recovery (McNett, 1987). Friedland and McColl (1992) summarised that stroke survivors might experience three sources of stressful events: (1) the same stressful life events as anyone else in the general population; (2) serious illness effects of the stroke itself; (3) a cluster of events following stroke, in particular, dealing with changes upon returning home such as changes in functional performance, family roles, employment and financial status. These events tend to be negative and beyond the individual's control, thus adding to the resultant stress (Friedland and McColl, 1992). Stressful events and unmet needs can result in the disruption of an individual's appraisal of the events leading to psychological distress, reduction in motivation or non-compliance with a rehabilitation regimen. Hence, potential positive rehabilitation outcomes are threatened. Nevertheless, one may argue that not every stroke survivor, who experiences these changes becomes depressed or distressed. This suggests that there may be some factors that modify the effects of stress on some stroke survivors. White, Richter and Fry (1992) tested a theoretical model of psychosocial adaptation to chronic illness. Their findings suggest a number of factors that might alter the relationship between stress and health (rehabilitation) outcome. Apart from intrinsic factors such as genetic endowment, personality, coping ability, value of and attitude towards health and illness, extrinsic factors such as social environment and social support also play an important role in the recovery process.

Social support has become an important research topic among health professionals in recent years. Much of the research interest in social support has been stimulated by its direct or moderating effect on adaptation to stressful situations. When confronted with a serious illness such as stroke, the person has to face the consequences of the illness and adapt to the new situation. As social support is a relatively accessible resource, it has been utilised as an intervention to the promotion of adaptation and recovery from illness (Glass and Maddox, 1992; Friedland and McColl, 1992; White, Richter and Fry, 1992; Glass, Matchar, Belyea and Feussner, 1993; Ho and Woo, 1994; McColl and Friedland, 1995; Mok-Suen, 1998). Social support is appealing as a therapeutic medium in addressing some of the stresses that result from illness (Friedland and McColl, 1992). Recently, specific social factors, such as social support, are acknowledged in stroke outcome studies to examine its predictive value on the long-term outcome (Gibbon, 1991; Glass and Maddox, 1992; Friedland and McColl, 1992). The following sections of this chapter explore the concept, measurement and function of social support in the context of stroke rehabilitation.

2.5 The role of social support on health and well-being

Current concerns with cost-effectiveness and rationalisation in the allocation of health care resources emphasise the need for critical examination of stroke recovery outcome and its predictive factors. Under the concept of cost containment within the health care system, studies of illness and social support have received the attention of social scientists as well as health professionals to a greater extent than any other psychosocial variable (Glass and Maddox, 1992). Findings demonstrate effects of social support on a variety of stressful life situation and health problems.

2.5.1 Beneficial effects of social support on health and well-being

Findings from Isacsson, Hanson, Ranstam, Ranstam and Isacsson (1995) indicate that social support in terms of a social network, availability of material and information is an independent predictor of the prevalence of daily neck pain and low back pain after retirement. This finding supports the argument that a lower degree of social support (i.e. poorer resources) is related to a higher susceptibility for lack of perceived control over the situation, which in turn lowers the capacity to cope with or handle the increased demands of daily life including pain (Isacsson et al., 1995). Consistent with the above findings were social support studies on various health aspects, for instance, a positive relationship between spousal support and shorter recovery periods in women after mastectomy (Lindsey, Norbeck, Carrieri and Perry, 1981). Social support was also found to have a beneficial effect in various populations, for example among unemployed males, pregnant women, the bereaved and people with mental and physical illness (Gottlieb, 1981; Friedland and McColl, 1992; Glass, Matchar, Belyea and Feussner, 1993; Mackenzie, 1998). Again, social support was reported to have a positive effect on health maintenance practice and life-style changes such as smoking cessation, leisure time physical activity and alcohol consumption (Hanson, Isacsson, Janzon, and Lindell, 1990; Hanson and Isacsson, 1992). Research on the aged shows that social support has important consequences both for physical and for psychological health status (Chi and Boey, 1994; Ho and Woo, 1994). In addition, Blazer (1982) studied the influence of three types of social support (namely, perceived social support, frequency of interaction and availability of attachment) on the mortality among people of 65 years and above. All three dimensions of support are associated significantly with mortality. In particular, perceived support, or lack of it, shows the strongest relationship. The availability of a confidant has been shown to protect against depression after a decline in social interaction and loss of social roles among the elderly and after bereavement. Thus, there is evidence that social support may be important in the well-being of people in general and of the aged in particular, and that it may be especially relevant in relation to depression (Turner and Noh, 1988).

2.5.2. Paradoxical effects of social support on health and well-being

Although social support is heralded as a way of helping people with a life crisis, it is probably true that counter-supportive or paradoxical effects can also occur. In fact, the assumption that benefits are accrued from the network proportional to its size has been criticised because availability of potential support may not reflect actual support that can be utilised in a stressful situation. Moreover, this assumption often fails to take into account the possibility that some ties may be detrimental or counter-supportive. It has been reported that some network members exhibit negative interaction that might inhibit support-seeking behaviour, which in turn negatively influences psychosocial adaptation (Clinton, Lunney, Edwards, Weir and Barr, 1998). Therefore, the unidirectionally positive interpretation on social networks may be a false dichotomy. Members within the networks can facilitate as well as inhibit supportive behaviour and relationships (Kaplan, Cassel and Gore, 1977). For this reason, measuring the quality of sources of support, in terms of perceived support and satisfaction, is more important than just measuring its quantity, such as size of the network and frequency of contact.

Norbeck (1988) has also indicated that social support may have a paradoxical effect if it is not introduced at the right time and at an appropriate level according to the clients' perceived needs. "Support which is intended by the provider to be positive, may be negative either because the objective outcome of the support provided is negative or the recipient of the support perceives the support negatively." (Norbeck, 1988, p.29) Examples might include overprotection, reinforcement of health damaging behaviour or sick role behaviour and assistance provided on demeaning or debilitating terms. Hence, in the study of social support, this is another important area that requires further research. The paradoxical effect of social support must be better understood to permit intervention and/or prevention (Clinton et al., 1998).

2.5.3. The importance of perceived support on health and well-being

The majority of social support studies have focused on measures of types and sources of support and their effects on health consequences. Nevertheless, these studies have left a question unanswered, namely, that health outcomes differ even among individuals with similar quantity and quality of supportive activities and social network. This may lead to a need for further examining social support in its phenomenological context, based on the beliefs that support is effective only to the extent that it is perceived (Friedland and McColl, 1992). Perceived support refers to two issues: (1) the individual's belief that there is someone he or she can rely on when needed; (2) the individual's subjective appraisal of the available support. In other words, the degree to which the person is satisfied with the type and/or amount of support received. Both perceived and actual support may have different effects on health, psychological functioning and social reintegration (Schaefer, Coyne and Lazarus, 1981). Also, satisfaction with support depends on who gives what to whom and when that happens. Perceived social support involves an evaluation of whether and to what extent the supportive activities and relationships are helpful. This refers to the satisfaction with the timing, source, quantity and quality of support. Within this framework, quantity refers to the objective evaluation of the availability, frequency and intensity of contact or services whereas quality refers to the subjective evaluation of perceived closeness, dependability and reciprocity.

In summary, knowledge on various effects of social support in a variety of health problems has provided researchers with a greater understanding of social support and its role in the promotion of recovery and adaptation to illnesses. Additional questions include the comparability of social support studies, as the concepts and definitions of social support vary among studies. The next section further explores the conceptual component of social support.

2.6 Social support concept and definition

Relevant literature shows that social support is a concept that has been studied by many researchers with different definitions, theoretical specifications and measurement scales. In conventional terms, social support refers to assistance rendered by people of one's social network such as family, friends, co-workers and neighbours. The term 'social support' has been used in many ways, representing many different concepts varying from objective aspects, such as provision of material supplies and monetary support (Ragsdal, Yarbrough and Lasher, 1993) to subjective aspects, such as feelings of belonging to a shared network (Cobb, 1976; Schaefer, Coyne and Lazarus, 1981).

Different concepts of social support lead to difficulties in precise definition, which in turn limit the extent to which existing research findings can be integrated and generalisations made. Some definitions are primarily subjective and focus on emotional issues. For instance, Kaplan, Cassel and Gore (1977) define social support as the degree to which the needs for affection, approval, belonging and security are met by others. Consistent with Kaplan's definition, Sarason, Shearin, Pierce and Sarason (1987) see social support as '...existence or availability of people on whom we can rely, people who let us know they care about us, value us and love us' (p.127). Turner, Frankel and Levin (1983) define social support as the experience of being cared for and loved, valued and esteemed, part of a network of mutual obligation and, more importantly, being able to count on others when need arises. Here Turner introduces the concept of 'need' that reflects an objective or instrumental component of support referring to the provision of aids to meet the need. Kahn (1985) further elaborates on the instrumental component on the definition where he defines social support as interpersonal transactions that express affect, affirmation and aid. Apart from the objective and subjective aspects, Barrera, Sandler and Ramsay (1981) introduce the reciprocal relationship in social support, where social support is viewed as '... people who supplied resources and the individual's subjective appraisal of the adequacy of support' (p.74). A more recent definition from Glass, Matchar, Belyea and Feussner (1993) is 'the sum of social, emotional and instrumental exchanges with which an individual is involved having the subjective consequence that an individual sees him or herself as an object of continuing value in the eyes of significant others' (p.64). To this end, the cognitive (perceived availability of support) and behavioural (received support) constructs should be distinguished.

Despite the diverse definitions and concepts of social support, one could argue that there is commonality in understanding the issues. The distinction between quantity and quality of support is well recognised. The latter has a greater impact on recovery. Most researchers concur that social support refers to social transactions that involve reciprocal relationships that are given and received by the members of the network creating a sense of belonging. Other commonality includes the assumptions that social support refers to interpersonal interactions in providing emotional support, actual tangible assistance or information to facilitate coping in everyday life, especially in response to stressful situations.

Therefore, social support has emerged as a complex and multidimensional concept that can be summarised and viewed from two aspects: Behavioural aspects encompass actual support which can be provided to an individual in various forms such as material, informational and financial support. Cognitive aspects encompass the perception by an individual of the availability of support by others which may or may not exist when need arises (Keeling, Price, Jones and Harding, 1996). To elaborate, the difference between behavioural and cognitive aspects of social support is that behavioural aspects (actual support provided) have a context-specific nature, i.e. the support given or received is in response to particular needs. Therefore, individuals differ in their needs and desire for support and their support seeking/receiving activities. On the other hand, cognitive aspects of social support relate to the assessment of the person's evaluation of the quality of the supportive relationships. In other word, the 'cognitive appraisal of being reliability connected to others' (Keeling, Price, Jones and Harding, 1996, p.77). Combining the behavioural and cognitive interpretations, Friedland and McColl (1992) suggest a contemporary view of social support in a broader context where social support has been defined as 'the experience or information that one is loved and cared for, valued and esteemed, and able to count on other should the need arise' (p.574). According to this definition, social support can be examined in two ways: First, its phenomenological context, based on the belief that support is effective only to the extent that it is perceived. Second, its multidimensional perspective that includes types of support, sources of support and dimensions of support (Friedland and McColl, 1992). The former highlights the subjective appraisal of or satisfaction with the support. The latter multidimensional perspectives of social support highlights the structural and functional aspect of support.

2.7 Distinctions between social network and social support

Social networks (the structural aspect of support) and social support (the functional aspect of support) are sometimes used inter-changeably in social support literature but they should be distinguished. Social network describes the structure of a social relationship and the interrelationships between individuals within the network. Social support, on the other hand, explores the functionality of social relationships in cognitive aspects (perceived support) and behavioural aspects (actual support). To elaborate, social network and social support are dialectically related to each other. In fact, social network underlines social support and sets its limits, whereas social support gives the meaning and function of the social network of an individual. Together these factors can help sustain an individual's ability to function in a stressful environment through expanding the resources of the individual (Isacsson et al.,1995).

2.7.1 Social network

Early studies mainly focused on social networks. Social network refers to the density, size and degree that the individual belongs to or senses his/her feeling of membership or position of trust within a formal or informal group (Ragsdale, Yarbrough and Lasher, 1993). Pioneers of social support studies, Kaplan, Cassel and Gore (1977) suggested a number of properties of social networks that might be relevant to health. These include marital status, numbers of close friends and relatives, and membership of community organisation. Many epidemiologists have studied social network to predict all-cause mortality rate in a large population (Ho and Woo, 1994; Chi and Boey, 1994).

Four types of networks were identified by Bernard et al. (1990) namely: (1) The emotional support group composed of a few intimates; (2) The larger support group involving reciprocity of favours; (3) The global network encompassing the first two and consisting of all people known by an individual; (4) The network of those outside the global network who could provide information about community resources (Stewart, 1993, p.9). It was generally believed that network size is associated with the amount of support and positive health outcome. However, Schaefer, Coyne and Lazarus (1981) claim that if only structural measures of social network are used to indicate benefits of social support, three questionable assumptions might lead to misinterpretation of or lack of understanding of social support: 1. Members in the social network are always supportive; 2. Having a relationship is equivalent to getting support; 3. Benefits are directly proportional to the size and range of the network.

Sources of support emerge from social networks. The literature shows that there must be an interaction of at least two individuals for supportive activity to occur (Kaplan, Casse and Gore, 1977; Hill, 1991; Ragsdale, Yarbrough and Lasher, 1993). The source of support is closely dependent upon the person's social network. Glass, et al. (1993) suggested that the availability of a network of community contacts and source of support had positive implications for psychosocial adjustment. Yet perception and satisfaction with social network and support were very individualised. While different sources are perceived as being more or less helpful, other sources of support cannot substitute for deficiencies in family support. Nurses and other health professionals are trained to be and are considered as one of the major sources of support. Nonetheless, their support might not be always available, especially after the person is discharged from the health care setting. In fact, once the stroke patient survives the acute phase and enters the rehabilitation phase, spouse and close family members are the central resource (McColl and Skinner, 1984; Ho and Woo, 1994; Chi and Boey, 1994). However, while many findings considered close relatives and loved ones as the best and usual sources of support (Caplan, 1974; Ragsdale, Yarbrough and Lasher, 1993), Friedland and McColl (1992), Clinton et al. (1998) suggested somewhat controversially that the support from more remote community contacts, such as friends, neighbours, work colleagues and health care providers, is more meaningful in terms of promoting adjustment than the support of family and close friends alone. While the direct (physical) care and support were mainly provided by the family, emotional and informational support are related to friends and groups as well as health professionals.

As the source of support plays a central role in influencing the effectiveness of a support-outcome relationship, there is a need to include all members in the support network in every phase of stroke recovery studies (Keeling, Price, Jones and Harding, 1996). Friedland and McColl (1992) suggested five sources of support that should be considered in social support studies, namely, personal (defined as the most significant relationship in the person's life, such as spouse and family); friend; community (such as neighbours, work colleagues, service people, etc.); groups (such as church-related, recreational, ethnic and self-help group, etc.); professional (such as doctors, therapists, nurses or social workers). Among the five categories, Friedland and McColl (1992) found that spouse and friends accounted for the largest proportion of social support providers. Others included relatives, church members and professional caregivers. Such a description provided a structural perspective of social support for further examination of the social functions of network members in response to a stressful situation.

2.7.2 Social support

Most social support researchers have assumed that feelings of intimacy derived from close social network members are important to health and well-being. Yet, social support has a number of independent components serving a variety of supportive functions. The functional content of relationships in the support network can be elaborated in different typologies, namely practical support, emotional, informational and appraisal support. Assessment of the functional aspects of support provides a framework for identifying possibilities for interventions (Cohen and Syme, 1985, McColl and Friedland, 1989 and 1995; Clinton et al., 1998).

Social support includes four functional aspects: tangible, informational and emotional support and social companionship. The intent of all types of support is to promote survival and increase vitality so that the individual maintains strength or endures (Ragsdale, Yarbrough and Lasher, 1993). **Tangible support**, or instrumental support, includes provision of needed material, costs and supplies. It includes taking over duties or doing a chore for needy persons. **Informational support** includes giving advice and gaining access to new knowledge and skills which could help a person solve a problem or clarify goals and ways to achieve them. Informational support is considered as one of the important elements in facilitating positive rehabilitation outcome by suggesting alternative solutions to a problem. Schaefer, Coyne and Lazarus (1981) further suggested that forms of informational support include providing feedback about how a person is doing. Giving such feedback could help the recipient maintain a social identity and a sense of social integration. **Emotional support** includes reassurance, sharing emotional burdens through sympathy or empathy, providing encouragement and expressing concern. Emotional support contributes to the feeling that one is loved and cared about, which helps the recipient sustain a sense of intimacy, attachment and self-esteem and reinforces feelings of self-worth. The contemporary view on social support recognises that emotional support is one of the most important types of support (Ragsdale, Yarbrough and Lasher, 1993; Hill, 1991; Lakey and Cassady, 1990; Peteet, 1982). **Social companionship** includes companionship for social and leisure-time activities. It is a particularly important function of support to a person with chronic illness as network size may be diminished as a result of long-term illness. Social companionship may also serve as an emotional support function, as it indicates caring and is not viewed as resulting from obligation (Stewart, 1993). In reviewing the relevant literature, it was found that many studies emphasised the attachment and affiliative functions of support over the instrumental and material support functions. However, the association between different types or functions of support and health outcomes were not identified. It is believed that it may be useful to assess emotional, tangible, informational and companionship support separately in relation to health outcome and to assess their interrelationships.

In addition, the need for different types of support function is context-specific, which means that the support given or received should correspond with particular needs throughout the process of stroke recovery. As illustrated by Schaefer, Coyne and Lazarus (1981), some stressful situations may be better resolved by simply providing some tangible aid or a service, for instance, offering ambulating aid and domicillary service at home. However, other stresses such as a blow to self-esteem may be better managed by providing emotional support, for instance, being there to listen; giving positive regards; showing a willingness to accept the person's disability. This is done in such a way that the person is less vulnerable to depression and loss of motivation. Therefore, different types of support to offer or receive vary in response to individual needs and the stage of recovery. For this reason, one should consider the potential in developing social support measures that are capable of distinguishing different types and functions of social support over a period of time during the long process of stroke recovery (Schaefer, Coyne and Lazarus, 1981).

To summarise, the mode of social support operation and its effect on health outcomes may vary with the type of support function involved. For this reason, there is potential value in developing measures capable of distinguishing multiple functions of social support at different periods in stroke recovery.

2.8 Support specificity

A more complex social support interaction was identified by Shinn, Lehmann, and Wong (1984), namely, that effects of social support which were intended by the donor to be supportive might not be perceived as such by recipients. One may occasionally receive unwanted or inappropriate help that is perceived as infringing one's sense of autonomy or diminishing one's self-esteem. Shinn, Lehmann and Wong (1984) suggested that different stresses engender needs for different types of support, and that specific sources of support are differentially appropriate for each of these needs. The model of "support specificity" elaborated by Cohen and McKay (1984) further suggested the importance of matching social support and individual circumstances along five elements: amount, timing, sources, structure and function.

2.8.1 Amount of support

Too little support in a needed situation may jeopardise recovery and adjustment to the stressful situation. This concept is well understood. Nevertheless, it is not uncommon to notice that too much support may be problematic. For example, too much attention and physical assistance may foster dependence and sick role behaviour. Revension, Wollman and Felton (1983) found that perceived high levels of emotional support were associated with low self-esteem and submissiveness among cancer patients. Therefore, the amount of support must be maintained at the right mix between support and challenge for people with chronic illness or disability. Such argument is supported by Riegel's findings. Riegel (cited by Ragsdale, Yarbrough and Lasher, 1993) reported that support among patients recovering from myocardial infarction was most effective when support was balanced with challenge.

2.8.2 Timing and function of support

As mentioned previously social support is situation specific. The timing and types of support may change over time throughout the disease process. For instance, Bronstein (1991) and Gibbon (1991) reviewed evidence that stroke survivors at different stages of recovery needed different types of support. Immediately after a stroke, emotional support and tangible support for ADL were important. Later, support aiding reintegration to social activities was important. The reorganisation of social role was of value at the final stage of recovery. Support provided prematurely might not be perceived as useful by the recipients. Specific example can be drawn from patient education on home care in acute in-patient settings without assessing the patients' concern and readiness to learn.

2.8.3 Sources of support

Shinn, Lehmann and Wong (1984) highlighted that different sources of support might vary in effectiveness under different situations. If a source of support is seen to be inappropriate then its potential value is decreased. This may be demonstrated by a friend (lay person) giving advice on recovery potential and progress, in contrast to the same advice given by a nurse or therapist. Similarly, according to Friedland and McColl (1989) and Clinton et al. (1998), a spouse is a key confidant and could not be effectively substituted by other confiding relations. Additional evidence shows that a person afflicted with terminal illness frequently makes a conscious choice either to remain in the original network of healthy individuals or to select a support system of others in a similar situation (Mok-Suen, 1998).

2.8.4 Structure of support

The structure of a social network also corresponds with an individual's situation. As previously mentioned, chronic illness has a bi-directional impact on one's social network and social support. It is commonly found that the network size of those with chronic illness decreases as time passes. At the later stages of illness, the social network is often confined to the spouse and immediate family.

To summarise, understanding the context-specific characteristic of social support is important. It is suggested that using social support as an intervention to promote health outcome should begin with an understanding of the differential effects of social support that match or fail to match individual circumstances within the dimensions of amount, timing, functions, sources and structure in different stage of stroke recovery.

2.9 Approaches to assessing social support

Review of empirical studies on social support and its impact on individuals' health and well-being indicates that there is a diversity in approaches and measures for assessing social support, resulting in a lack of consistency in research findings. The intuitive nature of social support is one of the main obstacles to a more unified approach to research (McColl and Skinner, 1988). The concept, precise meaning and measurement of social support are still being debated in relevant literature. This lack of agreement about operational and conceptual definitions contributes to the present inability to compare and summarise approaches and empirical effects of social support on health. Problems of precise meaning and measurement in the contemporary study of social support have prompted subsequent researchers to deal with social support in a multi-method approach and to develop measures of support based on social support concept and definition (Antonucci, 1985).

2.9.1 Study approach

Methodological differences in previous studies can be attributed to the multidimensional nature of social support. Some study approaches had focused on quantifying the structure and function of a set of people, who were either potential or actual sources of support within the social environment. Assessment of the structural dimension of support often involved applications of social network analysis (Stewart, 1993). Other study approaches focused on assessing individuals' subjective appraisal of support. Assessment involved capturing individuals' satisfaction and subjective appraisal to the adequacy of received support (Clinton et al., 1998; Barrera, Sandler and Ramsay, 1981; Norbeck, 1988). A third approach focused on the specific behavioural activities between the support providers and recipients. Different types of support activities were examined, for example, assisting others in mastering emotional distress, sharing work tasks, providing information and/or material aids.

Effective attempts at measuring social support depend upon an understanding of the precise nature of what is being measured, of the factors which impinge upon the support interaction and also of the support needs of the population addressed. In the work on the development of a more systematic approach to assess social support, Barrera and his colleagues (1981) recognised the multi-dimensional nature of social support. They recommended a multi-method approach to assess social support rather than adopting the traditional single approach. The multi-method approach would allow for a more precise specification of which dimensions of support were predictive of adjustment and adaptation for a specific study population (Barrera et al., 1981). Barrera further indicated that the simultaneous use of several different social support measures might capture a more comprehensive picture for improving our understanding of the social support processes, which appeared to have important implications for adaptation to chronic illnesses in our communities.

2.9.2 Measuring social support

To examine substantive issues concerning the role of social support in maintaining and promoting individuals' health and well-being, research and clinical trials have been developed to test models of social support intervention. However, before this can be effectively accomplished, a method of valid and reliable measurement of social support is required. Social support should be appropriate to the concept and definition of social support, the research aims and design, as well as to the target population.

Reviewing social support studies conducted by nurse researchers, it was evident that only 28% of these studies used social support measuring scales that had established validity and reliability (Norbeck, 1988). Most of the research did not properly define social support in operational terms. Social support measures developed by nurse researchers were reviewed by Stewart (1993). Only one third of the measures reported in these studies included results of reliability and validity. In addition, it is worthwhile to note that there are many different instruments devised by nurse researchers, yet only a few have been used in studies other than those in which they were first described. In other words, nurse researchers infrequently use tested instruments included in social-psychological literature developed from other disciplines or studies. Norbeck (1988) concluded that validated general instruments should be used, unless situation-specific measures are warranted, so that findings can be compared.

Review of social support studies conducted by other disciplines also evidenced the proliferation of social support measures. It was found that the measures might not reflect the multidimensional construct of social support to include the structural and functional aspects. Community psychologists and epidemiologists have traditionally been interested in structural features that could be changed to enhance the health and social functioning of entire populations. For instance, the number of persons in the network, participation in church and social groups, interactions among peers as well as employment. Alternatively, researchers of behavioural sciences have often conceptualised social support in cognitive terms. Perceived support and emotional aspects of support have been the focus of measure in these studies. Virtually all studies of social support have included the global statement to measure the attachment and affiliative functions of social support. However, the specific elements of social support relevant to the study population were inconsistently measured. The duration of support, mutual receipt and provision of support, costs associated with negative support and evaluation of satisfaction with support are infrequently assessed.

The following paragraphs in this section explore relevant social support measures that have been used in studies on chronic illnesses or incapacitating diseases. Social support measures used in these studies can be categorised into three main focuses: social support resources (i.e. social network); supportive interaction (i.e. different types of supportive activities and function) and the subjective appraisal of support.

Chi and Boey (1994) adapted the Lubben Social Network Scale (LSNS) (Lubben, 1988) for a local study assessing social networks among elderly living in community dwelling. The concept on social support in this study focuses on the support resources in one's natural network. The LSNS measures three major components of support resources, namely, friends, relatives and confidants. In Chi and Boey's

(1994) study, social network and support were examined by assessing family size, living arrangement, size of the household, satisfaction with the living arrangement as well as the frequency of receiving different types of supportive activities including psychological support, provision of actual help and financial assistance, giving advice, etc. The network member(s) who provided the different types of support was also identified. Open-ended questions were included for subjects to provide a list of people who were "significant" or "important' to them.

Suurmeijer et al. (1995) examined the use of the Social Support Questionnaire for Transactions (SSQT) among patients with rheumatoid arthritis. In their study, social support was conceptualised as an actual transaction or exchange of resources between at least one recipient and one provider of these resources and was intended to enhance the well-being of the recipients. A list of 28 items measuring actual supportive interaction was developed based on two basic functions of support, namely, emotional (affection, sympathy, companionship) and instrumental (advice, practical help and financial assistance) type of support. The internal consistency (Cronbach's alpha) of SSQT ranged from 0.64-0.76. SSQT has also been tested for inter-rater reliability as well as comparisons across countries. Seven hundred and forty four patients with rheumatoid arthritis from four different European counties (France, Norway, The Netherlands and Sweden) were involved in the study. Findings supported the claim that SSQT was a useful instrument for international comparative research.

Barrera et al. (1981) employed a broad definition of social support in the development of social support measure: The Inventory of Socially Supportive Behaviours (ISSB) measures different types of supportive activities between network members considering transaction or exchange of resources (mastering emotional distress, sharing tasks and teaching skills) during the preceding four weeks. Responses for the 40 items of ISSB were rated on a 5-point Likert scale. The internal consistency of ISSB (alpha coefficient was 0.96). The test-retest reliability of ISSB ranged from 0.45 to 0.91.

In a study measuring social support satisfaction and network indices, Barrera et al. (1981) introduced the Arizona Social Support Interview Schedule (ASSIS) to measure other facets of social support. ASSIS provides information concerning people who supply resources (i.e. the support network) and individuals' subjective appraisals of the adequacy of support. In the ASSIS, six categories of social support activities form the basis for questions in the interview guide, including material aid; physical assistance; intimate interaction; guidance; feedback and social participation (engaging in social interactions for fun, relaxation and leisure) (Berrera et al., 1981). In addition, the assessment approach for identifying social network membership differed substantially from methods used in other studies such as Chi and Boey (1994) and Suurmeijer et al. (1995). In the ASSIS, subjects were asked to name people who specifically serve supportive functions. In other words, it provides a method for identifying individuals in their network who have or are perceived to be the source of support for specific needs. Apart from that, the ASSIS also calls for the identification of people in the support network who are the sources of interpersonal conflict. This element is particularly important in social support studies on chronic or disabling illnesses, as a major source of support could also constitute a major source of strain (Stewart, 1993). Hence, in the ASSIS, three social network indices can be generated: the perceived support network; the utilised support network and the source of conflict within the network.

To summarise, literature review of the approach to assessing social support highlighted the fact that, although many previous publications and research reports on social support have been published in the past decades, most of them lacked precise meaning, concept and an operational definition of social support on which the research could be based. Therefore, findings of individual studies can only provide a fragmented picture about social support, which is not sufficiently comprehensive to reflect the process and mechanism through which social support operates in enhancing an individual's health and well-being. Based on the multi-dimensional characteristics of social support, Barrera et al. (1981) suggested a multi-method approach in assessing social support. The simultaneous use of several social support measures was recommended so as to capture a broader picture of specific dimensions of social support. Such an approach may also allow for a more precise specification of which aspects of support are predictive of an individual's adaptation to chronic illness and promotion of well-being.

2.10 Conclusion

Stroke is extremely common in industrialised societies and ranks among the top four causes of death (Department of Health, 1996). Presently, it is commonly recognised that survival from stroke cannot be equated with freedom from impairment or disability. Because of the magnitude of stroke, it simply re-emphasises the fact that there is a very large population of stroke survivors who may be disabled and require continuing specialised care (Brandstater and Basmajian, 1987). Hence, the psychosocial consequences of disability after stroke are emerging as a growing concern. Recovery from stroke involves more than the physical return of function; most stroke survivors require significant psychosocial adaptation.

In spite of numerous research studies on stroke outcome, there are many questions concerning the way to measure the stroke recovery. The general functional outcome, as determine by independence in activities of daily living, is rather superficial particularly if that is to be the decisive outcome measurement of the effectiveness of stroke rehabilitation. In fact, many factors other than the physical aspect also contribute to post-stroke outcome. These include the survivors' psychosocial functioning, in particular, the presence of depression; the social aspects of living, vocational status and life satisfaction. Moreover, the availability of social support, in particular family support and economic resources, as well as the availability and quality of rehabilitation have a significant influence on post-stroke outcome. Yet, it is only during the last decade that the time course and pattern of recovery from stroke have been studied in defined populations.

Although the physical, psychological and social impact of stroke on the individual is devastating, little is known about the holistic well-being of stroke survivors, particularly on longitudinal basis. In addition, several major issues that have been addressed theoretically must be explored in the real world. Therefore, central issues need to be addressed in future research including: (1) conceptualising a holistic sense of well-being; (2) expanding stroke outcome measures to include functional and psychosocial perspectives that contribute to the well-being of an individual; (3) assessing the change of the stroke survivor's perceived well-being over time; (4) following stroke survivors in a longitudinal study to explore predictive factors for the perceived well-being of stroke survivors in the process of stroke recovery.

The revisit of a theoretical framework for studies of social support for people with chronic or incapacitating illness emerges when considering measuring instruments. It has been established that the lack of linkage between theoretical, conceptual and operational definitions of social support is a common deficiency when developing or selecting social support instruments. Several sources and functions of social support are consistently found to be affecting health outcomes. Yet, there is still a great deal to learn about how they work to lower/raise levels of distress or to facilitate/impair physical health. Based on the recommendations from previous publications, the implications for future studies of social support include: (1) by specifying the context specific situations relevant to the recovery process, and identifing sources and functions of social support by further research, we may be able to advance our understanding of the role of social support in stroke recovery; (2) social support assessment should include and compare the cognitive aspects (perceived support) as well as the behavioural aspect (received actual support); (3) there is a pressing need for researchers to refine their hypotheses beyond the general yet questionable assumptions that social relationships somehow protect against all psychological and physical health problems. In fact, conceptual work is needed to consider the source and negative effects of support; (4) social support is context-specific and assessment of social support needs to be made on a longitudinal basis to capture the changing focus. Such information is particularly important in order to discover the therapeutic nature of intervention which is specific to the client and the situation; (5) to avoid further proliferation of social support instruments, Norbeck has suggested that nurse researchers should expand efforts to modify measuring instruments and enhance the relevance of existing social support instruments through supplementation (cited by Stewart, 1993). Norbeck (personal communication, 1997) further emphasised that social support measures adopted or adapted for ethnic or cultural groups must be translated and tested for relevance and appropriateness in order to establish validity.

CHAPTER THREE

CONCEPTUAL FRAMEWORK

3.1 Introduction

Based on different views and interpretations on stroke recovery reviewed in the last chapter, a conceptual framework is developed in line with the aims and objectives of this study. The conceptual framework and its components will be described and explained in this chapter.

3.2 Well-being of stroke survivors and its relating factors

Although stroke implies a single diagnosis, it is a syndrome causing a wide range of consequences that threaten the well-being of a stroke survivor. Despite the overwhelming nature of the physical impairments that accompany a stroke, stroke recovery is not analogous to the restoration of neurological or physical function. The psychological response towards loss of function as well as socioeconomic consequences experienced by stroke survivors are equally important. Assessing stroke recovery requires a more comprehensive view, to include the stroke survivor's perception of his/her own sense of well-being.

Functional status, emotional status, participation in social activities and life satisfaction throughout the recovery process contribute to a more comprehensive sense of well-being of a stroke survivor. Functional status refers to the performance in activities of daily living which reflect a stroke survivor's independence in his/her own natural living environment (Smith and Clark, 1995). Recovery from resultant neurological impairment may not be possible as the neurons in the brain cannot regenerate. This makes the ability to develop new skills and regain independence in self-care after a stroke more significant. The presence and level of depressive moods experienced by a stroke survivor may reflect the emotional status. Post-stroke depression is a particularly relevant form of psychological dysfunction and is a significant component of the emotional well-being of a stroke survivor. Similarly, participation in social activities is an important element in the well-being of a stroke survivor. Participation in social activities (or the social aspects of living) includes the vocational status and participation in leisure-time activities. Even though a stroke survivor achieves independence in activities of daily living and accepts the resultant disability, it is not uncommon that he/she still feel a loss of vitality, simply because the stroke makes him/her unable to perform his/her pre-morbid role and responsibility. Life satisfaction is based on a positive appraisal of the current situation. Specific to stroke survivors, life satisfaction refers to the state of health and functional independence, respect and recognition from others as well as role fulfillment.

Using these four perspectives in assessing an individual's perceived well-being is consistent with Roger's (1970 cited by George, 1995) assumptions about the human being. The human being is viewed as a unified whole that is composed of subsystems, namely, genetic endowment, bio-physiological functioning, psychological, social and spiritual elements. However, aggregation of individual subsystems is ineffective in enabling one to determine the properties of the human being as a whole. The human being can be distinguished from other species in that a human is a thinking being that continuously interacts and interprets its internal and external environments. Therefore, the distinctive properties of the human being as a whole are different from its parts or subsystems (George, 1995). Roger's assumptions have a strong parallel with the understanding of holism which implies that the whole is greater than the sum of the parts (Erickson, cited by George, 1995). Based on the holistic view on human being, well-being of the stroke survivors in this study is conceptualised to include four interacting perspectives, namely, functional status, emotional status, participation in social activities and life satisfaction. Comparable with Roger's view (1970 cited by Geroge, 1995), functional status reflects the bio-physical function of an individual; emotional status reflects the psychological aspect of an individual; participation in social activities reflects the social aspects of living; life satisfaction refers to an individual's appraisal of his/her life situation.

Many factors contribute to recovery from a stroke. Commonly recognised elements are: (1) clinical factors related to stroke, including the onset, type, site and side of stroke, degree of neurological impairment, presence of co-existing illness and complications; (2) treatment factors such as length of hospital stay, rehabilitation modalities and provision of post-discharge health care services. Nevertheless, an unanswered question still exists. Stroke recovery outcome differs even among individuals with commonality in clinical, treatment and demographic background. This implies that some variables may contribute to stroke recovery and the perceived well-being of a stroke survivor.

The unexpectedness and uncertainty of stroke and its sequential disability produce a major stress to stroke survivors. When considerable psychosocial adjustment is required, well-being is threatened. If resources in the form of social support can be called upon, adaptation to life after the stroke may be enhanced. In this study, social support is considered to be the realisation or experience of being cared for and loved, valued and esteemed, and being able to count on others should the need arise (Friedland and McColl, 1992).

Contemporary views on social support are complex and multidimensional. Social support in stroke recovery can be categorised within a three-dimensional model, namely: functional aspect of support, structural aspect of support and satisfaction with the support received. Tangible, informational and emotional support and social companionship form the functional aspect of social support. The number and sources of network members, whom the stroke survivor identifies as being able to rely on in needy situations, form the structural aspect of support. Apart from family and health professionals in the initial period of recovery, sources of support can be extended to include more remote community contact such as friends, neighbours and colleagues. Satisfaction with support refers to the subjective appraisal of the adequacy and helpfulness of the support received.

Friedland and McColl (1992) asserted that social support is effective only to the extent that the support is perceived. Based on this belief, two levels of interpretation of support were identified, namely, cognitive interpretation of support (the perceived support) and behavioural interpretation of support (the actual support). To elaborate, cognitive interpretation of support refers to a stroke survivor's subjective perception of the potential availability of support by others that may or may not exist when needs arise. Behavioural interpretation of support refers to the actual support or hands-on help that was provided by others.

With the concept of social support in this study, an individual's available support resources, in terms of different types of support functions and support network, are identified. An individual's satisfaction with the availability of support is captured.

3.3 Conclusion

In this chapter, the conceptual framework of the study was described and its components were explained. To summarise, a stroke survivor's perceived well-being is composed of four perspectives, namely functional status, emotional status, participation of social activities and life satisfaction. Apart from a stroke survivor's demographic characteristics and clinical and treatment conditions, social support is believed to have a role in the recovery process and the perceived well-being of stroke survivors. In view of the complexity of the social support concept, a contemporary view of social support was highlighted. The components of social support include cognitive and behavioural interpretation of functional aspect of support, structural aspect of support and the satisfaction with received support. A schematic presentation of the conceptual framework is illustrated in Figure 3.1.

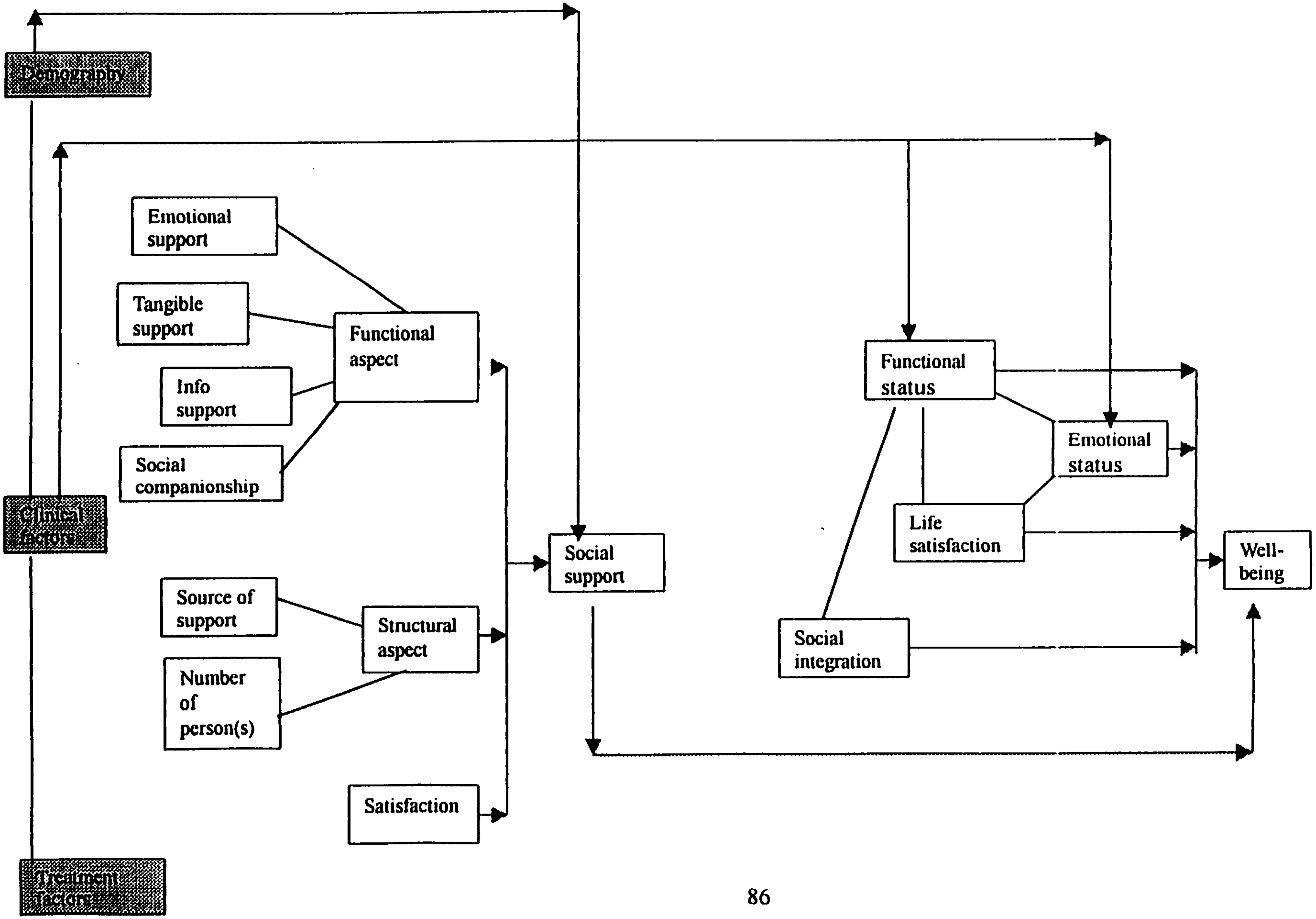

Figure 3.1 Conceptual framework for the study

CHAPTER FOUR

METHOD OF STUDY

4.1 Introduction

Stroke is a health problem that is sudden in onset and results in impairment of body functions. Recovery from stroke often tends to be long. Findings from previous literature also concluded that stroke recovery should be studied on a longitudinal basis so that comparison becomes possible in assessing the progression or regression of physical and psychosocial functioning, as well as an individual's subjective sense of well-being. In this Chapter, the research variables will be operationally defined. The research design, sampling method, instruments, data collection methods as well as ethical considerations will be discussed with reference to the aims and objectives of this study. Specific to the characteristics of stroke population, mechanisms to promote participation and safeguard data quality will also be addressed.

4.2 Operational definition of research variables

Key dependent and independent variables specific to the aims and objectives of this study are defined as follows:

Stroke

The World Health Organization's definition of stroke was adopted in this study. Stroke refers to a clinical syndrome consisting of a constellation of neurological findings, sudden or rapid in onset, which persist for more than 24 hours, with no apparent cause other than vascular origins, either ischaemic or haemorrhagic (Aho et al., 1980). Confirmation of diagnosis was made by medical practitioners based on either CT scan findings or clinical manifestations.

Perceived well-being (dependent variable)

Specifically for stroke and stroke recovery, the interpretation of well-being in this study is closely linked with the World Health Organization's holistic view on health: A state of complete physical, mental and social well-being (WHO, 1984). Four perspectives were used in assessing a stroke survivor's perceived well-being, namely, functional status, emotional status, participation in social activities and life satisfaction. The following is the elaboration of each perspective:

Functional status refers to a stroke survivor's performance in carrying out activities of daily living in his/her natural living environment. Functional status is assessed by a stroke survivor's level of independence in mobility and self-care, such as continence, grooming, walking, transferring, bathing, etc. (Collins, Wade, Davies and Horne, 1988; Gibbon, 1991; Gompertz, Pound and Ebrahim, 1994; Chang and Mackenzie, 1998).

Emotional status refers to a stroke survivor's emotional state, indicated by whether the person experienced post-stroke depressive mood, which is a relevant form of psychological dysfunction after stroke (Brontein et al., 1986; McColl and Friedland, 1989; Long et al., 1992; Tuomilento et al., 1995). Emotional status was assessed by a stroke survivor's depressed affect, positive affect, somatic and retarded activities as well as interpersonal interactions (Radloff, 1977; Ebrahim, 1990; Poon, 1997).

Participation in social activities refers to the social aspects of living including vocational status, participation in social and leisure-time activities. Participation in social activities was assessed by comparing the types and levels of activities at the premorbid and current state. For examples, house-bound versus out-door activities, social outings, contact with friends and family members as well as resuming pre-morbid roles and hobbies (Ebrahim, 1990 and Barker, 1994).

Life satisfaction referred to a stroke survivor's appraisal of the current life situation. It was assessed by 5 major elements, namely, physical health status; being independent; a sense of affinity; role functioning as well as appraisal of life as a whole (Clinton et al., 1998).

Social support (independent variable)

The definition of social support in this study was adopted from McColl and Friedland's (1989) interpretation where social support referred to "the information or experience of being cared for and loved, valued and esteemed, and able to count on others should need arise" (p.58). In addition, Keeling, Price, Jones and Harding (1996) further elaborate on the contemporary view of social support to include behavioural interpretation and cognitive interpretation. Behavioural interpretation of social support refers to the actual hands-on help and support that is provided by someone (the received support). Cognitive interpretation of social support refers to the perception by an individual of the potential availability of support from others, which may or may not exist when needs arise (the perceived support).

Based on the above definitions, social support (both perceived and received support) in this study is assessed in three aspects, namely, the functional aspect of support, the structural aspect of support and an individual's satisfaction towards the support received. As an elaboration, the functional aspect of support is made up of different types of support, including emotional support, tangible support, informational support and social companionship. The structural aspect of support comprises the sources and the number of persons available for different support functions. Satisfaction with support is reflected by an individual's appraisal of the availability of support in the needed situation.

4.3 Research design

The study adopts a 6-month prospective design. Data were collected at two points in time namely the period immediately after the subjects survived the acute phase of the stroke and six months later. Each of the stroke survivors was first interviewed on admission to the rehabilitation settings (first phase) and then was interviewed again six months later (second phase).

A six months period was considered because findings from previous relevant studies indicated that both neurological and functional recovery could best be achieved in the first six months after a stroke (Andrews, Brocklehurst, Richards and Laycock, 1981; Skilbeck, Wade, Hewer and Woods, 1983; Kotila, Waltimom Niemi, Laaksonen and Lempinen, 1984; ; Reding and Potes, 1988; Smith, 1990; Duncan et al., 1994). This time course of recovery was further supported by the Copenhagen Study conducted by Jorgensen et al. (1995). The Copenhagen study was a large community-based prospective study. Findings showed that the best neurological and functional recovery outcomes were reached within 13 weeks from onset. After this time, no significant changes were observed (Jorgensen et al., 1995).

With reference to the aim and objectives of this study described in Chapter One, prospective design was considered because such design can reveal a time course of stroke recovery. The stability or change in the perceived well-being throughout the first six months recovery process can be examined. Factors affecting stroke recovery can also be identified. In addition, the relevant literature indicates that social support influences health and perceived well-being of an individual and conversely, disability resulting from stroke also influences social support (Glass, Matchar, Belyea and Feussner, 1992; White, Richter and Fry, 1992; McColl and Friedland, 1995; Mok-Suen, 1998). Following a group of stroke survivors over a period of time can reveal how mechanisms of support such as the functional and structural aspects of support as well as satisfaction with the support received may change throughout the course of recovery. The reciprocity in continuing close relationships in the first six months following a stroke can also be interpreted. This can add to the predictive power of influence of social support to the perceived well-being of the stroke survivors over time (Stewart, 1993).

4.4 Sampling

4.4.1 Sample size and sampling method

In Hong Kong, a territory-wide stroke registry is yet to be developed. In 1993 and 1994, there were respectively 19,070 and 20,813 patients discharged from hospital (including deaths) following new and recurrent stroke (Department of Health, 1996). Statistics indicate the incidence of stroke (no separate figure for transient ischaemic attack) to be approximately 14,000 (Hospital Authority, 1997).

To attain 80% statistical power with 5% error tolerance, the sample size was 90. One hundred and twelve subjects were recruited in the first phase of the study. This estimation was based on 10% mortality rate (Department of Health, 1996) and 15% drop out rate.

The subjects were obtained by convenience sampling from two rehabilitation hospitals on Hong Kong Island. The catchment areas for these two rehabilitation hospitals included the Eastern, Central, Western and Southern Districts of Hong

Kong Island. Potential subjects were transferred from two major acute hospitals on Hong Kong Island covering the same catchment areas once their acute medical condition became stable. The subjects who met the inclusion criteria were invited to participate in the study. In phase one, all face-to-face interviews were conducted in the in-patient rehabilitation settings. In phase two (i.e. six months after the acute phase of stroke), interviews were conducted in the subject's natural living environment, for example, at home or in the nursing home.

4.4.2 Sampling criteria

Sampling criteria list the characteristics essential for eligibility to be classified as a member of the specified population (Pilot and Hungler, 1991). The stroke survivors in this study were selected from the accessible population according to the following criteria:

Inclusion criteria

- Chinese, able to speak Cantonese or Mandarin;
- Had experienced the first occurrence of stroke (either ischaemic or haemorrhagic) as confirmed by medical practitioners based on either Computer Tomograhpic (CT) scan findings or clinical manifestations;
- Cognitively intact;
- Medically stable;
- Had functional problems that limit participation in previous activities.

Exclusion criteria

- Individuals with expressive or receptive aphasia or dysphasia were excluded from this study due to the face-to-face interview format.
- Individuals diagnosed with brain tumour were excluded. Space occupying lesions may produce clinical symptoms similar to stroke, yet the recovery outcome could be very different and was outside the scope of this study.
- Individuals who had a history of psychiatric illness were excluded because their perception and coping mechanism to stress related to the sudden occurrence of stroke could be different.
- Individuals who had a history of alcohol or drug abuse were excluded because previous literature indicates that these conditions might have a confounding effect on studying post-stroke depressive mood.
- Other causes which presented a stroke-like syndrome (e.g. subdural haematoma, epilepsy);
- Prior neurological impairment from neurological or other disease.

  The last two elements were excluded because they were outside the scope of this study.

4.5 Measurement of key variables

The following section describes the protocols, procedures and questionnaires that measure the key research variables according to the aims and objectives of the study described in Chapter One. In this study, they are referred to as "the instrument" and it is composed of four sections . They are presented as follows:

4.5.1 Demographic variables

The first section of the instrument assessed the subject's demographic profile. Variables adapted from a local community-based survey (Chi and Boey, 1994; Woo, Yuen, Kay, and Nicholls, 1992) included age (according to the date of birth indicated in the Hong Kong Identity Card), sex, religion, marital status, number of children, educational level, premorbid occupation, financial status and years of residence in Hong Kong.

Socioeconomic variables that related to stroke recovery were also included. For example, premorbid place of residence, living arrangement, type of housing and whether lift was available, as well as source of income.

4.5.2. Clinical variables

The second section of the instrument assessed variables related to a stroke and clinical conditions of stroke survivors. Information was obtained from two sources: physical assessment performed by the researcher as well as from the medical record.

Stroke variables include the date of onset, stroke type, side and location. Neurological impairment was assessed by the researcher including motor function (Bates, 1996), sensation (Bates, 1996), twelve pairs of cranial nerve functions, visual field involvement, gait and coordination, ataxia, neglect and sphincter control. Apart from the above, co-existing illness(es) and complication(s) resulting from a stroke were also assessed.

4.5.3 Social support variables

The third section of the instrument was to examine the social support variables. The interview guide was structured into four components: emotional support, tangible support, informational support and social companionship. In each component, three aspects of social support were examined, namely, the functional aspects (the level of different types of support received in the past four weeks), structural aspects (number and sources of person available and/or providing the support in the past four weeks) and the individual's subjective appraisal of the adequacy of support received.

The functional aspect of support was assessed with quantitative measures, adapted from the Social Support Questionnaire - Transaction (SSQT) (Suurmeijer et al., 1995), for the level of different types of support received by the stroke survivors in the past four weeks. There were nine statements in the emotional support component. Examples included expression of care and concern, providing positive feedback and encouragement, sharing the emotional burden with sympathy (Van Sonderen, 1990; Hill, 1991; Ragsdale, Yarbrough and Lasher, 1993). There were six statements in the tangible support component. Examples included provision of needed material and money, actual assistance in doing a chore for a needing situation such as taking over duty, assistance in household activities and transportation (Ragsdale, Yarbrough and Lasher, 1993; Van Sonderen, 1990). There were nine statements in the informational support component assessing the provision of advice, knowledge and skills that could help a person's problem-solving and realistic goal setting. Examples included information on stroke recovery progress, self-care, community assistance as well as ways to seek help in needy situations. There were four statements in the social companionship assessing the availability of companions for social and leisure-time activities. Social companionship can be expressed as attachment and affiliative types of support that signal caring and yet are not viewed as resulting from obligation (Stewart, 1993). Examples of social companionship included a companion for social gathering and leisure activities, a telephone call for social chatting and dropping in for a pleasant visit. The subjects were asked to identify the level of support received in the past four weeks using a 4-point Likert scale ranging from 1 (never) to 4 (very frequently). The total score ranges from 28 to 112, the higher the score, the better the support.

The structural aspect of support was assessed with open-ended questions adapted from the Arizona Social Support Interview Schedule (ASSIS) (Barrera, Sandler, Ramsay, 1981). There were six support needs relevant to stroke recovery, included in which were emotional support (expression of private feelings, provision of positive feedback), tangible support (provision of needed material, providing physical assistance for task(s) needing help), informational support (provision of advice and information) and social companionship (companion for leisure time activities, the opportunity to provide reciprocal help to others). For each support needs circumstance, the subjects were asked to name the person(s) whom they perceived to be the source of support. They were then asked to name this/these person(s) from whom they actually received help in the past 4 weeks. Two indices of network size were then generated: (1) the available networks (the number of persons perceived as being available for at least one type of support). (2) the utilised network (the number of persons reported to have actually provided at least one form of support) (Clinton et al., 1998). The subjects were then asked how satisfied they felt with the adequacy of support received on a three point ordinal scale, indicating their satisfaction with the support received in the past four weeks.

Assessing the support network specific to an individual's needs was justified and consistent with Caplan's (1974) concept of social support in the view of person-environment fit as well as Cohen and McKay's (1984) proposed model of "support specificity" that suggests the importance of matching social support and individual circumstances. Recent relevant studies by Shinn, Lehmann and Wong (1984), Chi and Boey (1994) and Ho et al. (1994) further elaborated that different stressors engender needs for different types of support, and that specific sources of support are differentially appropriate for different needs.

4.5.4 Perceived well-being

The fourth section of the instrument examined stroke survivors' perceived well-being. Perceived well-being, specifically for stroke and stroke recovery, was examined in four perspectives, namely, functional status, emotional status, participation in social activities and life satisfaction. Each of the perspective is described as follows:

Functional status

The Barthel Index (Mahoney and Barthel, 1965 cited by McDowell and Newell, 1996) was adopted to examine the independence in activity of daily living (ADL). It measured the functional health status of a person in terms of performance in the ten most common activities of daily living including: bowel and bladder continence, grooming, feeding, toilet use, transfer, mobility, dressing, bathing and walking stairs. The total score ranged from zero indicating full dependence to 20 indicating full independence in activities of daily living. The Barthel Index is a valid and reliable instrument. It is adopted for use in the present study because of its wide usage in the local rehabilitation settings (Kong, 1997; Ho and Woo, 1994; Woo, et al, 1992; Ho, 1991). In addition, the Barthel Index is currently used by the Hospital Authority as one of the outcome indicators in the development of the stroke registry in Hong Kong (Kong, 1997). The Barthel Index in internally consistent and Cronbach's alpha is 0.9 (Shah, Vanclay and Cooper, 1989).

Emotional status

The Centre of Epidemiology Study - Depression Scale (CES-D) (Radloff, 1977) was adopted for assessing an individual's emotional status. The CES-D scale is composed of 20 statements designed to measure an individual's current mood state and level of depressive symptomatology. Four emotional components were assessed including the positive affect, the depressed mood, somatic and retarded activities and interpersonal problems (Kuo, 1984). The CES-D scale has been used as a screening tool for assessing depression in stroke patients (Shiner et al., 1986). Using the conventional cutoff point at 16, the CES-D in stroke patients has been demonstrated to have 73% sensitivity and 100% specificity (Shiner et al., 1986). The CES-D has also been adopted in a local community-based study assessing the mental health status of the elderly in Hong Kong (Chi and Boey, 1994). The CES-D was extensively assessed by Chi and Boey (1994). CES-D was found to have very good validity discriminating between a normal group and a clinical group ($t=3.6$, $p<0.05$) (Chi and Boey, 1994). The CES-D was also found to be reliable (Cronbach's Alpha = 0.8, Split-half reliability = 0.74) for application in local studies (Chi and Boey, 1994).

In the CES-D scale, there are twenty statements using a 4-point Likert scale (0 = never, 3 = very frequently) to measure the level of depressive mood within the past 7 days. Total score ranges from 0 to 60 with higher score indicating more depressed. Using the Cronbach's alpha, the internal consistency of CES-D ranges from 0.84 to 0.9 (Radloff, 1977; Ying, 1988; Chi and Boey, 1994).

Participation in social activities

The purpose of this sub-section was to compare an individual stroke survivor's premorbid social and leisure-time activities with the current level of participation six months after a stroke. In the first phase data collection, stroke survivors were asked to identify activities that used to be done regularly before the stroke. Examples included participation in paid work, doing housework, looking after children and local shopping. The stroke survivors were also asked to identify their hobbies and leisure time activities. Examples included meeting relatives / family friends, playing mahjong, attending sporting events and social outings. During the second phase data collection, the subjects were asked to identify their participation in social and leisure-time activities in similar manner as described in the first phase interview. The subjects were also asked whether they had developed new activities or hobbies in which they had not participated before the occurrence of the stroke. Reported social and leisure activities were then compared. Data obtained from this sub-section provided descriptive information about the stroke survivors' social aspects of living after they returned to the community dwelling six months after the stroke. The stability or change in participation in social activities before and after the stroke could then be assessed.

Life satisfaction

Life satisfaction assessed the stroke survivor's state of positive appraisal to his/her current life situation. Clinton et al. (1998) designed 10 statements to assess an individual's appraisal of the current health status, independence in self-care, the respect and recognition received as well as the ability to fulfil the premorbid social role. The subjects were asked to answer using a 5-point Likert scale (1 = very dissatisfied, 5 = very satisfied).

4.5.5 Translation

Except for the CES-D scale, which has a Chinese version available (Ying, 1988), back translation was employed for the interview guide. The researcher translated the English version of the interview guide into Chinese. A bilingual person was then invited to re-translate the Chinese into English. The first and second English versions were then compared. Apart from differences in expression of some statements in the social support component, no major variation was found between the two versions.

4.6 Test of instrument

The following sections present the validity and reliability of the instrument used in this study.

4.6.1 Validity test

The validity of an instrument refers to the degree to which an instrument measures what is supposed to be measured according to the aim and objectives of the study (Polit and Hungler, 1991). A content validity test was employed in this study. A panel of five experts was invited to verify the content-related validity of the instrument against the aim, objectives and research questions of the study. A stroke client, who was cognitively intact, had experienced a moderate level of functional disability after a stroke and had completed secondary school education, was invited to participate in the content validity test. As this person had experience of a stroke, his opinion was considered valuable to the examination of the content validity of the instrument.

Social support measure

The expert panel examining the content validity of the social support measure was composed of one stroke client, one clinical nurse specialist in stroke rehabilitation, one community health nurse, one medical social worker and one academic expert in nursing and social support areas.

A written invitation explaining the aims and objectives of the study, research questions and social support measure was sent to the members of the expert panel. Each expert panel member was asked to review individual items in the social support scale and rate on a Likert scale ranging from 1 (irrelevant), 2 (somewhat relevant), 3 (relevant) and 4 (very relevant). The panel members were also requested to provide written comments or recommendations for items that they rated irrelevant or somewhat relevant.

The content validity index for the social support measures was 0.81. Based on the comments from the expert panel, the following areas in the social support measure were expanded:

1. Informational support component: Five statements were added to include informational support specific to the local health care service. These statements were: (1) People give you information about support groups for stroke survivors; (2) People tell you how to seek help in needy situations; (3) People give you information about the availability of community services after discharge from hospital; (4) People tell you where to buy rehabilitation aids.

2. As social support involves a reciprocal relationship, a mutual support element was added to the open-ended questions. The statements explore whether the stroke survivor was needed by others, such as looking after children, providing advice or helping with household tasks. The subject's satisfaction on the opportunity to help others was also explored.

3. Another comment from the panel was directed to the culturally specific issues on the social support scale. Assessment of social support needs to be social and culturally specific. A focus group was formed to critically examine the interview guide on social support measure. The focus group was composed of ten individuals from hospital and community rehabilitation teams. There were two nurses from in-patient setting, two nurses from community nursing service, one rehabilitation nurse specialist, one medical social worker, one representative from a community-based rehabilitation programme, one stroke rehabilitation physician and two stroke survivors (one male and one female) who were mentally intact and had completed secondary school education. Issues identified by the focus group were mainly the wording and expression of the social support measure. Based on the recommendations, the statements in the emotional support

component as well as social companionship component were modified so that expressions were comprehensible and specific to situations in Hong Kong.

Centre of Epidemiology Scale-Depression (CES-D)

A content validity test was conducted to examine the applicability of the CES-D scale in the screening of depressive mood for Chinese stroke survivors. The content validity panel was composed of one psychiatric nurse, one clinical nurse specialist in stroke rehabilitation, one community health nurse, one physician, one clinical psychologist and one local academic in clinical psychology. The content validity test for the CES-D scale was conducted using a similar approach as for the social support measure. The result (CVI) was 0.91. Some reviewers commented on the items relating to somatic symptoms, such as appetite and extra effort in performing tasks, because these symptoms may have resulted from the effect of physical disability rather than from depression. The researcher decided to keep those two items and use the full CES-D scale. This is because the scale has been adopted for use in measuring depression as one of the stroke outcome variables in other studies (Morris et al., 1989 and Shiner et al., 1986) and has demonstrated high sensitivity and specificity (73% sensitivity and 100% specificity) (Shiner et al., 1986) as mentioned in the previous section (Section 4.5.4). Adopting the full scale also makes comparisons among other studies possible.

The discriminant validity of the CES-D scale was tested in a community-based study on mental health status of the elderly in Hong Kong (Chi and Boey, 1994). Using the conventional cut off point at 16, CES-D scale demonstrated good discriminating power between the normal group and clinical group ($t = 3.6$, $p < 0.05$).

Barthel activities of daily living Index (BI)

The Barthel activities of daily living Index (BI) was used to assess the functional status of stroke survivors. The BI consists of ten items assessing the various physical functional abilities in ten activities of daily living: bowel and bladder continence, grooming, feeding, dressing, mobility, transfer, toileting, bathing and walking stairs. The composite score ranges from 0 to 20 where the higher the score the better the stroke survivor's independence in activities of daily living. BI has been used in Hong Kong as a measure of disability in clinical settings and research studies for many years (Leung et al., 1990; Ho and Donnan, 1991; Ho, 1991; Woo, Yuen, Kay, Nicholls, 1992; Ho and Woo, 1994; Chu and Pei, 1997). Recently, it has been adopted for use as one of the outcome indicators in the Stroke Registry in Hong Kong (Kong, 1997). The validity of BI has been established (Wade and Collin, 1988). Validated methods of administration include direct observation, interview (of patient, caregiver and nurse), telephone interview and self-administrated postal questionnaire (Collin; Wade, Davies and Horne, 1988; Wade and Collin, 1998; Gompertz, Pound and Ebrahim, 1994,).

Although BI is well validated and one of the most popular ADL scales, there are some difficulties in interpreting previous studies. First, various guidelines and scoring systems exist (Granger, Dewis, Peters, Sherwood and Barrett, 1979; Collin et al., 1988; Shah, Vanclay and Coopes, 1989; Gompertz, Pound and Ebrahim, 1994). Second, most studies did not publish the interpretation guideline. Third, when present interpretation guidelines were vague and not culturally specific. Therefore, in this study, the Barthel Index together with the scoring system and interpretation guidelines (modified from Collin, et al., 1988) were sent to the expert panel for content validation. The following comments, from one of the panel members who was an occupational therapist, addressed the issue of interpretation guidelines:

1. *The guidelines should include a general statement specifying their use for assessing a person's actual function versus a person's potential function i.e. assessing what a person does or what a person could do. This is because there is always the risk of discrepancy between the two.*

2. *The item of feeding involves cultural practice and, therefore, the interpretation guideline should be specific to this issue. In Chinese practice, an independent person is able to hold up a bowl and use chopstick to reach out for food. To both left-sided stroke and right-sided stroke persons, this "normal" practice can be a difficult task. The interpretation guide should spell out the accepted level of independence.*

3. *The item of dressing indicating "need help, but can do about half-unaided". The word "half" is vague. "Half" could mean putting on upper (or lower) garment half-unaided or simply with 50% of the effort but needing help in the other half. The guidelines have to be more specific.*

Based on the comments and recommendations from the expert panel, a general instruction was added to the interpretation guidelines specifying the following:

First, direct observation in a simulated environment is widely used in the clinical context for testing a person's ADL competence and potential functions by therapists. However, Gompertz, Pound and Ebrahim (1994) point out that differences are often observed between what a therapist thinks a patient can do and what they actually do in real life, because performance of tasks depends on motivation and the social situation. In line with the aim of this study as well as the World Health Organization's definition of disability, the measurement of disability in this study is specifically concerned with how people with impairments actually perform in the real world, which refers to people's performance in their normal living environment.

Further, direct observation of performance of some functional tasks takes time, and is difficult in clinical practice. For example, the assessment of bowel continence may not always be possible during the interview period. In addition, interpretation takes time because accidental bowel incontinence refers to frequency of incontinence over not more than once a week. As the main purpose of this index in this study wass to assess the person's perception of well-being in functional independence, asking the person himself/herself and verifying with other useful sources such as health care assistants, nurses, family members, cohabitants and domestic maids has been accepted as one of the validated methods of administration.

Second, in view of the comments from the expert panel, specific guidelines on feeding and dressing were specified as follows:

The guideline for interpreting independence in feeding was expanded to specify the acceptable level of independence to include the use of adaptive devices such as a spoon and non-slippery bowl to become independent in feeding self. The term "need help" was also specified to accommodate a variety of common Chinese foods to include needing help from others to divide food into smaller portions and to remove bones from fish or meat.

The guideline for interpreting independence in dressing was expanded to specify the term "need help, but can do half-unaided" to include help with buttons, zips, tying up shoelaces, etc. Apart from that, the person can put on some garments (upper or lower) by himself/herself.

4.6.2 Reliability test

The reliability of an instrument is the degree of accuracy and consistency with which it measures the attribute that it is intended to measuring (Polit and Hungler, 1991). Based on this concept, the reliability of the instrument in this study was assessed in three aspects: internal consistency (evaluated by means of Cronbach's alpha), stability (evaluated by means of test-retest and split-half reliability) and equivalence (evaluated by means of interrater reliability). Reliability tests of different measuring scales were conducted separately depending on the nature of the individual scale.

Social support measure

Forty family caregivers of stroke survivors, obtained by convenience sampling, were invited for a reliability test of a measure of social support. Family caregivers of stroke survivors were invited to take part in a reliability test specifically for stroke recovery. This was because family caregivers and stroke survivors may share similar needs and concerns for social support. The internal consistency of the modified social support measures as given by Cronbach's alpha was 0.84. Split-half reliability was 0.69. To assess equivalence, 15 subjects who were randomly obtained from the caregiver group were invited for an inter-rater reliability test. The two interviewers took alternate turns to conduct the interviews. While one interviewer conducted the interview, the other interviewer independently observed and recorded the same event using the social support interview guide. The correlation between the two sets of data was also calculated. The inter-rater reliability with Spearman's Rho correlation for social support measures was 0.92.

CES-D scale and life satisfaction scale

Forty healthy subjects were obtained by convenience to participate in the reliability test of the CES-D and life satisfaction scales. As both of these scales assess an individual's current level of depressive mood and appraisal of current life situation respectively, split-half reliability was employed. Split-half reliability in this subject group gave a Cronback's alpha of 0.87 for the CES-D scale. Inter-rater reliability was conducted using a similar approach as for the social support scale. Inter-rater reliability with Spearman's rho test for CES-D scale was 0.62 and life satisfaction scale was 0.68.

Barthel Index

Forty elderly subjects were obtained by convenience to participate in the reliability test of BI. The Barthel Index assesses the activities of daily living performance of individuals in their current living situation. The interview and assessment were conducted in the ward where subjects were currently staying. Inter-rater reliability was conducted using a similar approach as for the CES-D scale. Inter-rater reliability with Spearman's Rho test of BI was 0.99.

4.7 Data collection

Data collection was conducted through face-to-face interview and supplemented with physical assessment for clinical data. Face-to-face interview was considered to be the method of choice because the stroke subjects may encounter difficulty in writing as a result of hemiplegia and visual disturbance. Some elderly subjects may have difficulty in reading words. Further, through interview, the subject's way of knowing and of interpreting experiences became accessible to the interviewer. This was beneficial for the clarification of uncertain issues in relation to the interview guide. The process of interview was done using a structured interview guide (Appendix 4.1) that had been tested and validated in local settings. Supplemented physical assessment of the subjects included neurological assessment and inspection of possible post-stroke complications, such as, pressure sore, neglect, deformities, oedema, frozen shoulder and hemiplegic shoulder subluxation. All interviews were conducted using the same sequence of structured and open-ended questions. For questions that the subject's answer could be "yes" or "no", supplementary statements were included to probe for more information. The subjects were interviewed twice: immediately after the acute phase of the stroke (Phase I, T_0) and 6 months later (Phase II, T_1). Data collection was done mainly by the researcher with the help of one trained interviewer.

Phase I (T_0) data collection of the stroke subjects was done within one week of admission to the rehabilitation hospitals. Rehabilitation physicians and clinical nurse specialists were requested to inform the researcher of new admissions of first-time stroke survivors. The researcher then contacted the potential subjects who met the sampling criteria. The interviewer explained to the potential subjects the purpose of the study and their possible contributions. Ethical considerations such as participation on a voluntary basis and the subject's right to withdraw at any time without detrimental effect to their present and future health care service were explained to the potential subjects. The potential subjects were encouraged to ask questions and raise their concerns at any time before or during the interview. Written consent was obtained prior to the interview. To ensure privacy, face to face interviews were arranged to take place in a quiet area as recommended by the nursing officer in-charge of the ward. Phase II (T_1) data collection was done 6 months after the first interview, either in the out-patient department, at the subject's home or in the nursing home. The data collection procedure in phase I was replicated using a similar approach.

4.7.1 Training and supervision of interviewer

Prior to data collection of the study, the researcher conducted a two-week training session for the interviewer. During the first week, the purpose of the study, the use of the interview guide, techniques of interviewing the stroke subjects and requirements of confidentiality were covered. The interviewer also underwent special training on physical assessment skills and techniques (Appendix 4.2 and 4.3) in order to standardise the procedure for neurological assessment and functional assessments as well as the subjective qualitative assessments of areas such as the extent of neglect, distal oedema, joint stiffness and swallowing difficulty. A videotape on neurological assessment for stroke patients was also provided as reference.

During the second week, ten sessions were organised to ensure standardised administration of the interview guide and the sequence and procedure of the interview was modeled, practised and supervised. The researcher evaluated the interviewer while conducting an actual interview and assessment of a subject. Solutions of problems encountered in the fieldwork were also discussed.

All completed interview guides were checked for completeness and accuracy. Coding, verification of data and data entry were done immediately after the fieldwork. Error checks and subsequent corrections were performed within a short time span. Such procedures also helped the identification of consistent patterns of errors, omissions and mis-interpretation.

4.8 Ethical considerations

Access for conducting the study had been obtained from the health care settings involved in this study. The subjects were informed of the purpose of the study. Written informed consent was obtained prior to the commencement of the interview (Appendix 4.4). Participation was on voluntary basis. The subjects were fully informed that they had the right to withdraw from the study at any time without any detrimental consequence to his/her current and future health care service.

The stroke subjects might find some questions in the interview guide sensitive or they might lead to emotional discomfort. Therefore, before the interview, it was explained that the subject had the right to refuse to answer questions which made he/she feel uncomfortable. When the subject demonstrated any emotional outburst during the interview, the interviewer discontinued the interview and allowed time for the subject to express his/her emotions. The interviewer accompanied the subject and/or provided support according to the subject's needs and preference. If the interviewer noticed that the subject had expressed suicidal thoughts, the interviewer would refer the subject to the charge nurse in the ward for close observation or referral to a clinical psychologist.

Confidentiality and anonymity were strictly assured. Subjects' personal information such as name, ID card number, address and telephone number were kept for phase II data collection. The information was kept separately and was restricted to the researcher's access only. Both subjects' personal information and the collected data were kept secure and their use was limited to this study only.

4.9 Conclusion

This chapter has explained and discussed the methods used in this study. To summarise, this study adopted a six-month prospective design. Specific to stroke and stroke recovery, the dependent variables and the independent variables were operationally defined. To improve the generalizability of the findings, the sampling criteria (both inclusion and exclusion criteria) were established with relevance to the aims and objectives of the study, as well as with reference to previous relevant literature. Measurements of key variables were discussed. Results of the validity and reliability of the instruments indicated that measures of the dependent and independent variables were within an acceptable level for data collection in this study. Chapter Five describes the feasibility and appropriateness of these proposed methods and procedures in the pilot study.

CHAPTER FIVE

PILOT STUDY

5.1 Introduction

The following pilot study was a trial run for the main study. It was developed similarly to the proposed study, using similar subjects and settings, the same set of interview guide and the same data collection procedures. The purpose of the pilot study was to assess the feasibility and effectiveness of the research method and data collection procedures as proposed in the main study. Data in the pilot study was analysed and scrutinised. Descriptive analysis of the pilot data gave the impression to the researcher that useful results would be obtained from the main study. The researcher would then make necessary revisions or refinements to the plan for interpretation of result during the data analysis process of the main study.

5.2 Study design

Research design for the pilot test was in line with the main study with modification. In the main study, a six-month prospective design was employed. The subjects were interviewed twice, immediately after the acute phase of the stroke (Phase I, T_0) and six months later (Phase II, T_1). However, a cross sectional design was adopted in the pilot study because the second phase data collection replicated that in the first phase. The subjects were interviewed once after the acute phase of the stroke using the same set of interview guidelines, sampling methods and data collection procedures as described in the main study.

5.3 Subject description

The pilot study was conducted from July 1997 to October 1997. Twenty subjects were recruited to the study. The subjects were obtained following the sampling criteria proposed in the main study except subjects have recurrent stroke. Because of the limited number of survivors experiencing the first stroke, recruiting survivors with recurrent stroke in the pilot study was considered as the method of choice so as to avoid contamination of potential subjects in the main study. The pilot study was conducted in a stroke rehabilitation unit of one general hospital.

5.4 Data collection procedure

Liaison between the Chief of Service, ward managers and nurse specialists was established as proposed in the main study. Face to face interviews took place in the wards at a convenient time recommended by the ward managers. Subjects were obtained by convenience sampling. The researcher approached the subjects and explained to them the aim of the study and their possible contributions to the main study. Ethical considerations identified in the main study were also explained and clarified with subjects. Written consents were obtained prior to data collection.

Timing of the interviews ranged from 45 to 90 minutes. The duration of interviews was longer than expected. Possible explanation was that individual stroke subjects varied in their concentration span, physical condition and the ability to express themselves. It was found that short breaks of five to ten minutes were helpful during the interview.

Eight out of 20 subjects demonstrated emotional upset during the interview when they encountered statements relating to their loss of function and self-care ability. Emotional upset was more obvious when they tried to describe their current emotional status and expectations for the future. The emotional response was understandable, especially among these subjects who were experiencing recurrent stroke. Extra breaks were provided. These subjects were encouraged to express their emotions or to cry if they wanted. The interviewer's support was found helpful even though the interviewer did not intervene but was just there and listened. Until the subject had settled down, the interview would not be continued. Of those subjects who were emotionally upset, seven settled down after a period and continued the interview. Only one subject expressed that he preferred to stop the interview. Another interview date was then arranged one week later, by then the subject felt more able to express his feeling and completed the interview.

As the interview guide was translated into written Chinese, experience in the pilot study demonstrated that there might be inter-interviewer variations when the interview was conducted in spoken Cantonese. During the interview, some subjects needed a more layman Cantonese style of communication

5.5 Findings of the pilot study

Due to the small sample size in the pilot study, data analysis was descriptive.

5.5.1 Demographic characteristics of the subjects

The mean age of this study sample (mean=67.35, SD=10) was comparable to those in other local or international studies. The majority of the subjects fell into the age range between 60 to 69 years (45%). However, three subjects (15%) were below the age of sixty. The youngest subject was aged forty-five years. The sample in this pilot study demonstrated that stroke was not limited to only the elderly population. The majority of the subjects were female (65%) who were local residents (80%), married (65%) and lived with their family before the current stroke (95%). The level of education was low among the subjects. Sixty per cent of the subjects had received no formal education; another 35% received education up to primary level. Forty-five per cent of the subjects were retired from work before the current stroke. For those who were working, 25% of the subjects engaged in unskilled manual labour and the remaining 25% were housewives. One subject was unemployed before the current stroke. Table 5.1 summarises the demographic characteristics of the stroke survivors in the pilot study.

Table 5.1. Demographic characteristics (N=20)

Demographic characteristics	n	%	mean	SD
Age (range)			67.35 (45-88)	10
Sex				
Male	7	35		
Female	13	65		
Marital Status				
Married	13	65		
Widowed	7	35		
Educational level				
No formal education	12	60		
Primary	7	35		
Secondary or above	1	5		
Occupation level				
Unemployed	1	5		
Retired before stroke	9	45		
Unskilled manual laborer	5	25		
Housewife	5	25		
Migrant				
No	16	80		
Yes	4	20		
Place of residence before stroke				
Hostel	1	5		
Home with family	19	95		

5.5.2 Clinical conditions of the subjects

Comparable to a recent study in Hong Kong, ischaemic stroke is the most common pathological cause of stroke (Huang, Chan, Yu, Woo and Chin, 1989; Mok et al., 1997). The findings of the pilot study showed that 90% of the stroke survivors had ischaemic stroke. As the result of the neurological insult, more than 50% of the subjects suffered from some degree of sensory, motor and cranial nerve impairment.

Seventy-five per cent of the subjects had other co-existing illnesses such as hypertension, arrhythmia, diabetes mellitus and hyperlipidaemia. Among these subjects in this pilot study, 45% experienced post-stroke complications. Consistent with other relevant studies, common complications include aspiration pneumonia, pressure ulcers, contracture deformity on upper limb and frozen hemiplegic shoulder. Table 5.2 summarises the clinical conditions of the subjects in the pilot study.

Table 5.2 Clinical conditions of the subjects (N=20)

Clinical conditions	n	%	Mean	SD
Stroke types				
Haemorrhage	2	10		
Ischaemic	18	90		
Stroke side				
Left	10	50		
Right	10	50		
Motor power				
Upper (range)			3.1(0-4)	1.02
Lower (range)			3.1(0-5)	1.37
Sensory				
Intact	8	40		
Impaired	19	55		
Cranial nerve involvement				
No	9	45		
Yes	11	55		
Visual field involvement				
No	18	90		
Yes	2	10		
Continence				
Continent	7	35		
Urinary incontinence	9	45		
Double incontinence	4	20		
Comorbidity				
No	5	25		
Yes	15	75		
Complication				
No	11	55		
Yes	9	45		

5.5.3 Independence in activity of daily living

Independence in performing activity of daily living is one of the important indicators of stroke recovery. A number of studies have found independence in ADL an independent predictor of mortality at 24-months after the stroke (Ho, 1991); discharge disposition and place of residence one year after stroke (Woo, Yuen, Kay and Nicholls, 1992; Whisnant, 1993; Mok et al.,1997) as well as perceived well-being and life satisfaction after stroke (Doolittle, 1988; Popovich and Stewart-Amidei, 1991; Kinney and Coyle, 1992; Bronstein).

The total Barthel scores of the subjects in the pilot study ranged from 3 to 17. Average total score was 8.15 (SD=4.63). Data was grouped according to Ho and Woo's (1994) data grouping: "Total score of 20 represents full independence in activities of daily living, scores of 15-19 represent mild functional disability requiring some help in activities of daily living, scores of 14 or less represent moderate or severe functional disability requiring considerable help or total dependence on others" (p.22). None of the subject from this pilot study was fully independent in activities of daily living. In fact, the majority of the stroke survivors (85%) had moderate to severe functional limitations requiring considerable help and assistance in activities of daily living.

As shown in Table 5.3, among the individual components in the BI, over 50% of subjects were independent in bowel control and feeding. However, walking stairs and bathing were reported to be two of the most dependent components among activities of daily living. No subjects could perform bathing independently and 90% of the subjects were unable to walk stairs. Urinary incontinence was reported by 65% and assistance was required for attending toilet needs by 85% of the subjects in this pilot study.

Table 5.3 Independence in activities of daily living (ADL) (N=20)

Independence in ADL	n	%	mean	SD
Barthel ADL Index			8.15	4.63
Bowel				
Incontinent	5	25		
Occasional accident	3	15		
Continent	12	60		
Bladder				
Incontinent	12	60		
occasional accident	1	5		
Continent	7	35		
Grooming				
needs help with personal care	10	50		
Independent	10	50		
Toilet use				
dependent	12	60		
needs some help	5	25		
Independent	3	15		
Feeding				
Unable	3	15		
needs help	6	30		
Independent	11	55		
Transfer				
Unable	1	5		
need major help	14	70		
need minor help	2	10		
Independent	3	15		
Mobility				
Immobile	4	20		
wheel chair independent	10	50		
walks with help of one person	3	15		
Independent	3	15		
Dressing				
Dependent	6	30		
needs help	10	50		
Independent	4	20		
Stairs				
unable	18	90		
needs help	2	10		
Bathing				
dependent	20	100		

5.5.4 Depressive mood

Depressive mood was assessed using the Chinese version of Center for Epidemiology-Depression Scale (CES-D) (Ying, 1988). The mean CES-D score in this pilot study was 29.4 (SD=10.26). Using 16 as the cut off score, the percentage of depressive-prone subjects in this group were 95%. Comparing the present pilot study with a previous relevant study done by Shinar et al. (1986), the percentage of depressive-prone subjects in this pilot study was much higher. One reason may be that the subjects participating in this pilot study were experiencing recurrent stroke and the majority of them suffered from complications resulting from the previous stroke.

Most international and local studies on community populations have found an increasing prevalence of depression with age. However, this study showed different findings. The younger group showed a higher average CES-D score. The possible explanation may relate to the occurrence of a physical disability at productive age. Females and those who were widowed showed higher average CES-D scores. Table 5.4 summarises the group means for depressive mood.

Table 5.4 Group mean for depressive mood by demographic characteristics (N=20)

Demographic characteristics	Depressive mood (CES-D scale)	
	mean	SD
Age		
<60	32.33	8.08
60-69	31.11	9.06
70-79	29.60	10.90
>/= 80	21.00	15.39
Sex		
Male	26.00	10.13
Female	31.23	10.25
Marital status		
Married	26.92	9.19
Widowed	34.00	11.25
Educational level		
No formal education	29.25	12.27
Primary education	29.57	7.57
Secondary or above	30.00*	0*
Occupation level		
Unemployed	45.00*	0*
Retired	28.33	12.20
Housewife	26.00	8.89
Unskilled manual laborer	31.00	6.31

* The cell has only one case

As shown in Table 5.5 and in contrast to some studies assessing depressive mood and the side of stroke, findings from this pilot study show that the subjects with right sided stroke reported experiencing a higher level of depressive mood. Comparable to most studies, those who had poorer independence in activities of daily living and a poorer level of life satisfaction experienced a higher level of depressive mood.

Table 5.5 Group mean and depressive mood by clinical factors

	Depressive mood Mean	CES-D scale SD
Stroke side		
left	26.50	10.82
Right	32.30	9.30
Barthel Index		
BI<12	32.27	8.70
BI>/=12	20.80	10.59
Life satisfaction		
Not satisfied	34.57	6.95
Satisfied	17.33	5.01

5.5.5 Life satisfaction

The subjects were asked to indicate their satisfaction on a 10-aspect life satisfaction scale developed by Clinton at al. (1995). Possible response ranged from 1 to 5 with the higher the score, the more satisfied was the subject. In this pilot study, the most dissatisfied aspects of life were the independence in self-care, followed by the current health status and the ability to resume the pre-morbid role.

5.5.6 Social Support

Social support is believed to have beneficial effects on the health and well-being of people and in particular, for those with disability and chronic illnesses. Good social support has been shown to lower the risk of mortality, make people more able to cope with stress and to maintain an optimal state of well-being (Friedland and

McColl, 1989; Friedland and McColl,1992; Ho and Woo, 1994; Chi and Boey, 1994; Clinton, et al., 1998). Findings from this pilot study show that the majority of the subjects were married (65%) and were living with their family (95%) prior to the current hospitalisation. All subjects have children, the number ranged from 1 to 10. The majority of the subjects have 2 or 3 children. Comparable to most studies, the main sources of income included government allowance (40%) and family members, such as spouse and children (25%). About 5% of the subjects depended only on themselves and their own savings for living.

As shown in Table 5.6, the size of available support from the subjects' social network varied ranging from zero to 4. The difference between perceived and received support was examined. Fewer persons had actually provided support when compared with the number of person perceived to be available when a needy situation arose. The main source of perceived and received emotional and tangible support was from spouse and immediate family, including sons, daughters and the in-laws. The majority of the subjects relied on health professionals for informational support. Spouse and friends were found to be the main sources of social companionship.

Table 5.6 Size of support network (N=20)

Size of support network	Mean	SD	Minimum	maximum
Emotional support				
Private feeling				
Perceived	1.70	1.08	0	4
Received	1.05	0.69	0	2
Positive feedback				
Perceived	2.20	1.24	0	4
Received	1.20	1.01	0	4
Tangible support				
Provision of needing material and money				
Perceived	1.65	0.93	0	3
Received	1.35	0.81	0	2
Providing physical help and assistance				
Perceived	1.40	1.05	0	4
Received	1.00	0.92	0	4
Informational support				
Provision of advice				
Perceived	1.70	1.45	0	4
Received	1.25	1.16	0	4
Social companionship				
Companionship for leisure-time activities				
Perceived	2.15	1.09	0	4
Received	0.95	1.00	0	3
Provide help to others				
Perceived	1.05	1.00	0	3
Received	0.70	0.92	0	3

The functional aspect of social support was measured on four types of support, namely emotional support, tangible support, informational support and social companionship. The higher the score, the better support received in the past four weeks. Among the four types of support, informational support was least available when compared with the other three (Table 5.7.).

Table 5.7 Level of different types of support received in the past 4 weeks (N=20)

Types of social support	mean	SD
Emotional support	2.87	0.36
Tangible support	2.49	0.68
Informational support	1.27	0.30
Social companionship	2.51	0.50

As shown in Table 5.8, comparable to other local and international studies, emotional support was more available to subjects who were married, with moderate dependence in activities of daily living and subjects in the oldest age subgroup. Tangible support was more available in subjects who were female, and those who needed considerable help or were dependent in activities of daily living. As 99% of subjects in this pilot study had been living with their family before current hospitalisation, comparison of the availability of support between those who lived at home and in institutions was not possible. In general, most of the subjects were satisfied with emotional and tangible support as well as the availability of social companionship. However, 96% of subjects reported that informational support to them was inadequate. An additional open-ended question on the need for information was asked. Most frequent issues addressed by the subjects include: the prognosis of recurrent stroke, self-care ability in the future, what happens if family members cannot look after them, how to seek financial assistance if needed, what did they eat or do wrong that lead to the recurrence of the stroke, how to handle shoulder pain and stiffness, whether there were other means for treating stroke (e.g. complementary medicine).

Table 5.8 Availability of social support by demographic characteristics and functional status (N=20)

Demographic variables	Social support mean (SD)			
	emotional	tangible	informational	companion
Sex				
Male	3.09 (0.29)	2.29 (0.87)	1.29 (0.24)	2.68 (0.51)
Female	2.74 (0.34)	2.62 (0.54)	1.27 (0.34)	2.42 (0.49)
Marital status				
Married	3.03 (0.32)	2.42 (0.79)	1.30 (0.32)	2.58 (0.48)
Widowed	2.60 (0.28)	2.77 (0.35)	1.28 (0.29)	2.24 (0.43)
Age				
<60	2.78 (0.29)	2.56 (0.51)	1.22 (0.11)	2.33 (0.29)
60-69	2.92 (0.35)	2.23 (0.80)	1.32 (0.38)	2.47 (0.52)
70-79	2.73 (0.44)	3.00 (0.41)	1.27 (0.32)	2.50 (0.47)
80-89	3.11 (0.31)	2.25 (0.59)	1.19 (0.17)	2.83 (0.77)
Independence in ADL				
moderate dependence	3.19 (0.26)	2.00 (0.60)	1.48 (0.57)	2.83 (0.76)
need considerable help/ dependent	2.81 (0.34)	2.59 (0.68)	1.24 (0.24)	2.46 (0.45)

5.6 Implications for the main study

Apart from testing an already-developed research plan, this pilot study has given the researcher experience with the subjects, settings, study method and data collection procedures. The results of this pilot study demonstrated that there was no major problem encountered. The proposed method and procedure can be implemented for the main study with the following recommendations:

1. The timing of the face-to-face interview should be lengthened to 60 to 90 minutes so as to accommodate different subjects' physical and emotional conditions as well as to allow regular 5-10 minutes breaks and extra breaks as requested by the subject.

2. The interviewer's support is extremely important during the interview, especially when the subject is upset. It is essential that the interviewer remain with the subject and acknowledge the subject's emotions in a supportive and positive way.
3. A facilitating environment that can provide privacy is recommended as some of the issues addressed in the interview are related to personal feelings and interpretations. The interview must be conducted without the presence of the subject's family member or significant others to allow the subject's free and honest expression during the interview.
4. A plan for training and supervision of interviewers during the interview should be considered prior to the main study. This is particularly important in relation to the sequence and procedures of the interview as well as the communication skills with stroke survivors.

CHAPTER SIX

THE RESULTS OF THE PHASE I STUDY

6.1 Introduction

Between December 1997 and August 1998, there were 112 stroke survivors, who met the selection criteria of this study, participated in Phase I. This Chapter presents the findings for those subjects who survived the acute phase of stroke. The data collected was based on the research questions stated in Chapter One. Background information, including the demographic characteristics and clinical conditions of the subjects will be presented in the first two sections of this Chapter. The stroke survivors' perceived well-being immediately after the acute phase of the stroke will be discussed. The availability of social support during the initial stage of the stroke will be presented and discussed in the following sections of this Chapter.

6.2 Demographic characteristics

Among the 112 subjects, there were 58 men and 54 women. The mean age of this study sample was 67.21 years, ranging from the youngest age of 34 years to the oldest age of 88 years (SD=10.6). Nineteen subjects (17%) were below 60 years of age. The majority of the subjects fell into the age range of 60 to 79 years (75%). The findings suggest that although the majority of strokes occur at an older age, stroke is not limited to the elderly population. Findings of this study are comparable to the age-specific stroke morbidity statistics in recent years in Hong Kong (Hospital Authority, 1997; Hospital Authority, 1996; Department of Health, 1996). Among those who were aged below sixty, more men (68.4%) than women suffered from stroke. Nevertheless, as the sample was obtained from two rehabilitation hospitals on Hong Kong Island, the age and sex distributions might not fully reflect that of the general stroke survivor' population in Hong Kong.

As shown in Table 6.1, more than half (61.6%) of the subjects were married, 28.6% were widowed, 8% were never married and 1.8% were divorced or separated. These findings are comparable to the demographic patterns of other local studies (Ho and Woo, 1994; Chi and Boey, 1994). Similar to the findings of the pilot study, the majority (83.9%) of the subjects lived at home with their families before the stroke. Only a small proportion (2.7%) of the subjects lived in institutions prior to the occurrence of stroke. The majority of the subjects had been living in Hong Kong for more than twenty years. Around 19% of the subjects were migrants from the Chinese mainland. Comparable to the sociodemographic profiles of other local studies, the education level was generally low among the subjects in this study (Ho, 1991; Ho and Woo, 1994; Chi and Boey, 1994). Nearly half (49.1%) of the subjects had no formal education and 33% had up to primary school education. Among those aged over sixty years, more women reported to have no formal education (Table 6.1).

Occupational status varied among the subjects. As shown in Table 6.1, around 50% of the subjects had retired from work. Around twenty per cent of the subjects participating in unskilled manual labour and 17% of the subjects were housewives. Nearly 80% of those aged below 60 had been engaged in paid work before the stroke. In addition, although the retirement age in Hong Kong is 60, about 31% of the subjects aged between 60-69 were still participating in paid work.

In relation to religious beliefs and consistent with Ho and Woo's findings (1994), less than 20% of the subjects had a formal religion. There were 16.8% Buddhists/Taoists and 12.5% Christians. Half of the subjects engaged in ancestral worship or folk beliefs. Around 20% of the subjects reported that they did not have any religious belief.

Table 6.1 Demographic characteristics (N=112)

Demographic Characteristics	n	%	Mean	SD
Age (range)			67.21(34-88)	10.6
Sex				
Male	58	51.8		
Female	54	48.2		
Marital Status				
Single	9	8.0		
Married	69	61.6		
Divorced	1	0.9		
Widowed	32	28.6		
Separated	1	0.9		
Educational level				
No formal education	55	49.1		
Primary education	37	33.0		
Secondary education	18	16.1		
Technical	1	0.9		
University	1	0.9		
Occupational Status				
Unemployed	4	3.6		
Retired	57	50.9		
Housewife	19	17.0		
Unskilled manual labourer	23	20.5		
Sedentary	3	2.7		
Skilled/technical	6	5.5		
Migrant				
No	91	81.2		
Yes	21	18.8		
Place of residence before stroke				
Hostel	3	2.7		
Home alone	6	5.4		
Home with flatmate/friend	7	6.3		
Home with relatives	2	1.8		
Home with family	94	83.9		

6.3 Clinical conditions

Comparable to the findings of the pilot studies and consistent with other local studies, ischaemic stroke is the most common and accounts for about 82% of the stroke in this study (Mok et al., 1997; Kay et al., 1995 and Huang, Chan, Yu, Woo and Chin, 1989). In relation to the stroke sub-types, findings from this study show that among the ischaemic stroke group, lacunar infarct accounted for 22% and internal capsular infarct accounted for 42.4%. All subjects from the haemorrhagic stroke group suffered from intracerebral haemorrhage, of which thalamic haemorrhage accounted for 38%.

Many studies have shown that stroke survivors suffer from a variety of neurological impairments, in particular, motor, sensory, cranial nerve, visual impairments and ataxia. Table 6.2 summarises the clinical conditions of the stroke survivors. The majority of the subjects suffered from contralateral motor impairment on both their upper and lower limbs. Motor power was assessed and recorded according to Bates (1994) (Appendix 6.1).as described in Chapter Four. The mean motor power of the upper and lower limbs of the subjects was 3.47 and 3.85 respectively. The median was 4 for both limbs, which means that 50% of the subjects suffered from mild to moderate hemiparesis on the contralateral side of both of their upper and lower limbs. Forty-two per cent of the subjects had sensory impairment on the contralateral side of their body. Eighty-two per cent of the subjects had one or more co-existing illnesses including hypertension, arrhythmia, hyperlipidaemia and diabetes mellitus. Around 94% of the subjects did not have any complications resulting from the stroke.

Table 6.2 Clinical conditions of stroke subjects (N=112)

Clinical conditions	N	%	Mean	SD
Stroke type				
Haemorrhage	20	17.9		
Ischaemic	92	82.1		
Stroke side				
Left	59	52.7		
Right	53	47.3		
Motor power				
Upper (range)			3.47 (0-5)	1.63
Lower (range)			3.85 (0-5)	1.25
Sensory				
Intact	64	57.1		
Impaired	46	41.1		
Absent	2	1.8		
Cranial nerve involvement				
Yes	46	41.1		
No	66	58.9		
Visual field involvement				
No	105	93.8		
Yes	7	6.3		
Ataxia				
No	107	96.0		
Yes	5	4.5		
Continence				
Continent	94	83.9		
Urinary incontinence	2	1.8		
Double incontinence	16	14.3		
Comorbidity				
No	20	17.9		
Yes	92	82.1		
Complication				
No	105	93.8		
Yes	7	6.3		

6.4 The stroke survivors' perceived well-being

The perceived well-being of the stroke survivors was reflected in four perspectives. They are the functional status, emotional status, participation in social activities and life satisfaction. Each of these is discussed in the following sections.

6.4.1 Functional status

The functional status of the stroke survivors was measured by their independence in activities of daily living using the Barthel Index (BI). The total possible score is 20. A higher score indicates a better performance in activities of daily living. The mean BI score was 13.54 (SD=5.92). The composite score from the BI was recoded according to the Wade classification (Wade and Hewer, 1987). There were five categories including: 20 representing full independence, 15 to 19 representing mildly disabled, 10 to 14 representing moderately disabled, 5 to 9 representing severely disabled and 0 to 4 representing very severely disabled. As shown in Table 6.3, 23% of the subjects had a full score of 20 indicating that these subjects were independent in activities of daily living. Thirty-two per cent of the subjects scored between 15 and 19, which means that they suffered from mild disability and required some forms of assistance. Forty-four per cent of the subjects had BI score of 14 or less, which means that these subjects required considerable help or full assistance from others in activities of daily living.

Table 6.3 Activities of daily living of stroke subjects (N=112)

Activities of daily living (Barthel Index)	N	%
Independent	26	23.2
Mildly disabled	36	32.1
Moderately disabled	16	14.3
Severely disabled	24	21.4
Very severely disabled	10	8.90

Among individual activities of daily living, as shown in Table 6.4, over 70% of the subjects were independent in feeding, grooming, bowel and bladder control immediately after the acute phase of the stroke. On the other hand, a majority of the subjects could not bathe themselves or walk up and down stairs (67.9% and 73.2% respectively) in the period after the acute phase of stroke.

Table 6.4 Individual item on activities of daily living (N=112)

Independence in ADL	n	%
Bowel		
Incontinent	14	12.5
Occasional accident	9	8.0
Continent	89	79.5
Bladder		
Incontinent	16	14.3
Occasional accident	10	8.9
Continent	86	76.8
Grooming		
Needs help with personal care	31	27.7
Independent	81	72.3
Toilet use		
Dependent	32	28.6
Needs some help	24	21.4
Independent	56	50.0
Feeding		
Unable	7	6.3
Needs help	16	14.3
Independent	89	79.5
Transfer		
Unable	8	7.1
Needs major help	29	25.9
Needs minor help	9	8.0
Independent	66	58.9
Mobility		
Immobile	23	20.5
Wheel chair independent	13	11.6
Walks with help of one person	17	15.2
Independent	59	52.7
Dressing		
Dependent	18	16.1
Needs help	34	30.4
Independent	60	53.6
Stairs		
Unable	72	64.3
Needs help	10	8.9
Independent	30	26.8
Bathing		
Dependent	76	67.9
Independent	36	32.1

Previous studies have indicated that there are differences in functional status among variables, including age, stroke type and side. Considering the differences between ADL independence among the subjects of different age groups, age was recoded to 4 categories for analysis (59 years or below; between 60 and 69 years; between 70 and 79 years and 80 years or above). Kruskal-Wallis ANOVA was performed. Results indicate that there is no significant difference in ADL independence among the subjects in the four age groups (Kruskal-Wallis H=2.641, df=3, p>0.05). To test the difference in ADL independence between the types of stroke and sides of stroke respectively, Mann-Whitney U tests were employed (U=919.5, p>0.05; U=1392, p>0.05 respectively). These results demonstrate that there is no significant difference in ADL independence between those who suffered from haemorrhagic stroke or ischaemic stroke, nor between those who suffered from left or right sided stroke.

Previous relevant literature indicates that various forms of neurological impairment affect stroke survivors' ADL independence. As discussed in Chapter Two, common neurological impairments included motor and sensory impairment, cranial nerve impairment, visual impairment, ataxia, incontinence and neglect. The level of motor power obtained from the subjects was recoded into three groups for analysis, namely none, weak and strong. Similarly, the level of sensory impairment was categorised into 3 groups (none, impaired and intact) for analysis. To determine whether the severity of motor impairment produced different levels of ADL independence, Kruskal-Wallis tests were performed. Significant differences in ADL performance were found among the motor impairment groups for upper limbs (Kruskal-Wallis H=15.246, df=2, p<0.001). To locate the differences, the post-hoc multiple comparisons procedure with Tukey's Honestly Significant Difference (HSD) test was performed. Differences were found between strong and none (mean difference=5.35, SE=1.44, p<0.001), as well as strong and weak (mean difference=4.07, SE=1.48, p=0.007). The Kruskal-Wallis test was also performed to test the differences among the severity groups of motor impairments for lower limbs. The results indicate significant differences among level of impairments of lower limbs on ADL independence (Kruskal-Wallis *H*=11.405, df=2, p=0.003). To locate the differences, post-hoc multiple comparisons procedure with Tukey's Honestly Significant Difference (HSD) test was performed. Differences were found between strong and none (mean difference=6.50, SE=1.95, p=0.001), as well as strong and weak (mean difference=3.47, SE=1.52, p=0.024). This means, for either upper or lower limbs, the subjects who had strong motor power either in their upper limbs or lower limbs performed better in ADL independence meassures. Significant differences of ADL independence were also found among level of sensory impairments (Kruskal-Wallis *H*=7.719, df=2, p=0.021). Post-hoc multiple comparisons were performed with the HSD test. Differences were found between absent and impaired (mean difference=-8.61, SE=4.16, p=0.041) and absent and intact (mean difference=-10.52, SE=4.13, p=0.012). This means the subjects who lost the sensory function on the affected side of their body had poorer performance in ADL independence.

To determine whether there were differences between levels of ADL independence and the presence of other forms of neurological impairment, Mann-Whitney U tests were performed. The findings indicated that there was a significant difference in ADL independence between those with cranial nerve impairment and those without (*U*=1138, p=0.021); as well as those with ataxia and those without (*U*=92.5, p=0.011). The results from Mann-Whitney U test also demonstrate that there is a significant difference in levels of ADL independence between subjects with and without the presence of post-stroke complications (*U*=171.5, p=0.018). In other words, poorer performance in ADL independence is found among subjects with the presence of cranial nerve impairment, ataxia or post-stroke complication.

6.4.2 Emotional status

Emotional status was measured by the Center of Epidemiology Studies-Depression (CES-D) scale. The mean score was 22.77 (SD=10.28). The higher score indicates a higher level of depressive mood that the subject has experienced in the previous seven days. When a conventional cut-off score at 16 is adopted for descriptive analysis, the result of this study show that 69.6% of the subjects scored higher than 16. This means the majority of the subjects are depressive-prone. The findings of this study were compared with other relevant studies. Discrepancies were found among the studies. For instance, the percentage of depressive-prone subjects in this study is higher than some studies, where prevalence of depression in post-stroke subjects was only 30%-40% (Wade, Legh-Smith and Hewer, 1987; Turner and Noh, 1988). Nevertheless, the findings of this study are consistent with numerous studies, in which about 60% of the first-time stroke survivors were reported to have mild to moderate post-stroke depression (Wade, Legh-Smith and Hewer, 1987; Argell and Dehlin, 1989; de Hann, Limburg, Van der Meulen, Jacobs and Aaronson, 1995; Duncan et al.,1997; Fuh, Liu, Wang, Liu, and Wang, 1997; Herrmann, Black, Lawerence, Szekely and Szekely, 1998). These discrepancies among studies could be attributed to the inherent problems in comparing the prevalence of post-stroke depression, as not all studies used the same measuring scale, sampling criteria and methods of data collection. In addition, the possibility of cultural variations in the expression of depressive mood should also be considered. Consequently, one must be cautious in adopting the conventional cut-off score without testing its discriminant validity in a local context. For this reason, the composite score of the CES-D scale was used for inferential analysis in this study.

The level of depressive mood among different demographic groups was examined. The difference between the sexes in the level of depressive mood was examined with the Mann-Whitney U test. The results show that there is no significant difference between men and women in the level of depressive mood. Kruskal-Wallis tests were employed for age groups, marital status, occupational status and educational background. The findings show that differences in the level of depressive mood are found among subjects with different educational backgrounds (Kruskal-Wallis H=6.4, df=2, p=0.041). Post-hoc multiple comparisons were performed with HSD test. Differences were found between the "primary school" group and "secondary or above" group (mean difference=6.89, SE=2.80, p=0.015). In other words, those who had completed secondary school education or above reported a lower level of depressive mood than those who had completed only primary school education.

The level of depressive mood among different clinical conditions was examined. Although early studies had shown that the prevalence of post-stroke depression was higher in patients with left-sided stroke (Novack, Graham and Satterfield, 1987; Robinson, Bolduc and Price, 1987), the findings of this study do not present the same picture. In fact, the findings of this study are more comparable with findings of House, Dennis, Warlow, Hawton and Molyneux (1990) and Fuh, Liu, Wang, Liu and

Wang (1997) that there was no significant difference in the level of depressive mood between subjects with left-sided stroke and right-sided stroke (Mann-Whitney U=1500.50, $p>0.05$).

The findings from this study also show that there is a significant difference in the level of depressive mood among subjects with different severities of motor impairment on upper and lower limbs respectively (Kruskal-Wallis H=7.067, df=2, p=0.029; and H=7.118, df=2, p=0.028 respectively). To identify the location of the differences, post-hoc multiple comparisons were performed with the HSD test. The locations of the differences in motor power are shown in Tables 6.5 and 6.6. The results show that the subjects with strong motor power in an upper limb reported a lower level of depressive mood than those who had weak or absent motor power in an upper limb. With regard to the motor power in a lower limb, the subjects with strong motor power in a lower limb reported a lower level of depressive mood than those who were weak in their lower limb.

Table 6.5 Table of mean differences using HSD test on motor power of upper limb

	Mean	None Mean difference (SE)	Weak Mean difference (SE)	Strong Mean difference (SE)
None	26.89	--	0.59 (3.42)	5.76 (2.65) *
Weak	26.29	-0.59 (3.42)	--	5.16 (2.72)
Strong	21.13	-5.76 (2.65) *	-5.16 (2.72) *	--

*p<0.05

Table 6.6 Table of mean differences using HSD test on motor power of lower limb

	Mean	None Mean difference (SE)	Weak Mean difference (SE)	Strong Mean difference (SE)
None	24.00	–	-5.13 (4.20)	2.42 (3.53)
Weak	29.13	5.13 (4.20)	–	7.55 (2.75) *
Strong	21.58	-2.42 (3.53)	-7.55 (2.75) *	–

* $p<0.05$

To determine whether there are differences between the level of depressive mood and the presence of other forms of neurological impairment, Mann-Whitney U test was performed. Findings demonstrate that there is a significant difference in the level of depressive mood between those with and without visual impairments ($U= 139.5$, $p=0.006$). In other words, those who suffered from visual impairment report a higher level of depressive mood.

The difference in the level of depressive mood among subjects with a different level of social support was also examined. Levels of support were recoded into three groups according to tertile. The highest tertile represents better support, the middle tertile represents moderate level of support and the lowest tertile represents poorer support. Findings from Kruskal-Wallis test support that there is a significant difference in the level of depressive mood among the subject groups in the area of emotional support (Kruskal-Wallis $H=9.418$, df=2, $p=0.009$). To identify the location of the differences, post-hoc multiple comparisons were performed with the HSD test. Significant differences were found between the means for “better emotional support” and “moderate emotional support” as well as between those for “better emotional support” and “poorer emotional support” (Table 6.7). In other words, those with better emotional support reported a lower level of depressive mood than the other two groups.

Table 6.7 Table of mean differences using LSD test on emotional support

	Mean	Poorer support Mean difference (SE)	Moderate support Mean difference (SE)	Better support Mean difference (SE)
Poorer support	23.28	--	-2.90(2.27)	4.80 (2.26) *
Moderate support	26.17	2.90 (2.27)	--	7.70 (2.33) *
Better support	18.47	-4.80 (2.26) *	-7.70 (2.33) *	--

* $p<0.05$

6.4.3 Life satisfaction

Life satisfaction of the stroke survivors was measured by asking the subjects to indicate their subjective appraisal with their current life situation, using the life satisfaction scale developed by Clinton and his colleagues (1998). The total score ranged from 10 to 50. The higher score indicate greater satisfaction with the current life situation. The mean score was 31.78 (SD=6.05).

A majority (62%) of the subjects indicated their dissatisfaction with their current physical health status. Around 42% of the subjects were dissatisfied with their independence in self-care. In contrast, the majority of the subjects were satisfied with the respect and recognition they received from others (75% and 74% respectively).

The level of life satisfaction among different demographic groups was examined. The different between sexes in the level of life satisfaction was examined with the Mann-Whitney U test. The results show that there is no significant difference between men and women in the level of life satisfaction. Kruskal-Wallis tests were performed for age groups, marital status, occupational status and education background. The findings show no significant difference among subjects with these demographic characteristics.

The differences in the level of life satisfaction of subjects with different clinical conditions were examined. Mann-Whitney U tests were performed to test whether there was a difference between subjects who suffered from neurological impairment and those who did not. As shown in Table 6.8, differences in the level of life satisfaction were found between those who had cranial nerve impairment and those who did not (*U*=1144.00, p=0.046); between those who had visual impairment and who did not (*U*=177.00, p=0.024); and between those who developed post-stroke complications and those who did not (*U*=130.00, p=0.016). A review of descriptive statistics shows that the subject group with cranial nerve impairment has a lower mean score than those without. A similar pattern is found in the visual impairment groups and post-stroke complication groups. In other words, the findings from this study show that the subjects with the presence of cranial nerve impairment, visual impairment and post-stroke complication were less satisfied than those who did not suffer from these three problems.

Table 6.8 Comparison table on life satisfaction and neurological impairments

Neurological impairments		Mean	*U*	P
Cranial nerve impairment	No	32.83	1144.00	0.046
	Yes	30.32		
Visual impairment	No	32.11	177.00	0.024
	Yes	27.00		
Post-stroke complication	No	32.10	130.00	0.016
	Yes	26.33		

Kruskal-Wallis tests were also conducted to determine whether there were differences among social support variables in the level of life satisfaction. Social support variables were recoded to three groups according to tertile, in the same approach as described in the previous section (6.3.2). Consistent with other relevant studies, the findings show that there are significant differences in the levels of life satisfaction among the subject groups in different emotional support categories (Kruskal-Wallis H=60223, df=2, p=0.045). Post-hoc multiple comparisons with HSD test were performed. Differences were found between those who have better emotional support and those who have moderate emotional support (mean difference=3.91, SE=1.40, p=0.006). Table 6.9 shows the result of the post-hoc analysis on emotional support. This indicates that among the emotional support groups those with better emotional support indicated more satisfaction with their current life situation than those who are in the moderate emotional support category.

Table 6.9 Table of mean differences using HSD test on emotional support

	Mean	Poorer support Mean difference (SE)	Moderate support Mean difference (SE)	Better support Mean difference (SE)
Poorer support	31.44	--	1.29 (1.36)	-2.62 (1.36)
Moderate support	30.14	-1.29 (1.36)	--	-3.91 (1.40) *
Better support	34.06	2.62 (1.36)	3.91 (1.40) *	--

$p<0.05$

6.5 Social support

The results are presented in the following three sections, corresponding with the three aspects of social support considered in the conceptual model: functional aspect of support, structural aspect of support and satisfaction with support.

6.5.1 Functional aspect

The functional aspect of social support was categorised into four types: emotional support, tangible support, informational support and social companionship. The subjects were asked to describe the frequency of support during the past four weeks on a 4-point Likert scale. The higher the score indicated the better support received. As shown in Table 6.10, comparing the four types of support functions, social companionship had the lowest mean. This means that the subjects in this study received the least support in the social companionship, when compared with other types of support functions such as emotional support, tangible support and informational support.

Table 6.10 Summary table for means of types of support functions (N=110*)

Social support	Mean	SD
Emotional support	25.38	4.21
Tangible support	13.33	4.64
Informational support	12.24	3.87
Social companionship	9.25	2.50

* Two missing data from one of the items in the tangible support section. Two subjects expressed that the question was not applicable to them since they had never encountered problems with money that required help from others even for a small amount. Therefore, these two cases were excluded from inferential analysis in this section.

Previous studies have indicated that there are gender differences in social support. However, the findings in this study do not show any differences between men and women in the level of social support, namely emotional support (U=1378.5, p=0.342); tangible support (*U*=1325.00, p=0.272); informational support (*U*=1471.50, p=0.688) and social companionship (*U*=1485.00, p=0.634).

The difference in the level of social support among different sociodemographic groups was examined with the Kruskal-Wallis test. Significant differences in the levels of emotional support were found among the marital groups (*H*=10.27, df=2, p=0.006). Post-hoc multiple comparisons with HSD test were performed. The findings show that there are significant differences between the single and married groups (mean difference=6.18, SE=1.39, p<0.001) as well as between the single and widowed groups (mean difference=5.57, SE=1.47, p=0.001). Table 6.11 shows the mean differences in the levels of emotional support for the marital groups. The findings suggest that those who are single receive less emotional support than those who are married or widowed.

Table 6.11 The mean differences in the levels of emotional support for the marital groups using the HSD test

	Mean	Single Mean difference (SE)	Married Mean difference (SE)	Widowed Mean difference (SE)
Single	19.89	--	-6.18 (1.39) *	-5.57 (1.47) *
Married	26.07	6.18 (1.39) *	--	0.62 (0.83)
Widowed	25.45	5.57 (1.47) *	-0.62 (0.83)	--

p<0.05

Significant differences in levels of tangible support were found among marital groups (*H*=8.40, df=2, p=0.015) and pre-morbid place of residence (*H*= 12.69, df=3, p=0.005). Tables 6.12 and 6.13 show the mean differences using the Tukey's Honestly significant difference (HSD) test on marital groups and pre-morbid place of residence for the level of tangible support.

Table 6.12 The mean differences using HSD test for marital groups and the levels of tangible support

	Mean	Single Mean difference (SE)	Married Mean difference (SE)	Widowed Mean difference (SE)
Single	10.22	--	-3.87 (1.61) *	-2.38 (1.71)
Married	14.09	3.87 (1.61) *	--	1.48 (0.96)
Widowed	12.61	2.38 (1.71)	-1.48 (0.96)	--

p<0.05

Table 6.13 The mean differences using HSD test for pre-morbid place of residence and the levels of tangible support

	Mean	Institution Mean difference (SE)	Home alone Mean difference (SE)	Home with cohabitants Mean difference (SE)	Home with family Mean difference (SE)
Institution	12.50	--	4.17 (3.62)	2.06 (3.47)	-1.45 (3.17)
Home alone	8.33	-4.17 (3.62)	--	-2.11 (2.34)	-5.61 91.87) *
Home with cohabitants	10.44	-2.06 (3.47)	2.11 (2.34)	--	-3.50 (1.55) *
Home with family	13.95	1.45 (3.17)	5.61 91.87) *	3.50 (1.55) *	--

p<0.05

From the above tables, the findings suggest that there is a significant difference between subjects who are single and those who are/were married, in the levels of tangible support received. Those who are/were married have better tangible support then those who are single. The findings also suggest that there are differences between those who lived with their family and those who lived alone, as well as those who shared accommodation with non-family related cohabitants. Those who lived with the family have better tangible support than the other two groups.

The findings of this study also show that different marital and educational backgrounds produce different levels of social companionship (Kruskal-Wallis *H*=18.62, df=2, p<0.001 and *H*=6.85, df=2, p=0.033 respectively) (Table 6.14 and 6.15).

Table 6.14 The mean differences using HSD test for marital groups and levels of social companionship

	Mean	Single Mean difference (SE)	Married Mean difference (SE)	Widowed Mean difference (SE)
Single	8.22	--	-1.78 (0.83)*	0.22 (0.88)
Married	10.00	1.78 (0.83) *	--	2.00 (0.5) *
Widowed	8.00	-0.22 (0.88)	-2.00 (0.5) *	--

$p<0.05$

Table 6.15 The mean differences using HSD test for education levels and levels of social companionship

	Mean	None Mean difference (SE)	Primary Mean difference (SE)	Secondary or above Mean difference (SE)
None	8.60	--	-1.16 (0.51) *	-1.45 (0.63) *
Primary	9.76	1.16 (0.51) *	--	-0.29 (0.67)
Secondary or above	10.05	1.45 (0.63) *	0.29 (0.67)	--

$p<0.05$

The results show that those who were married had better companionship support than those who were single or widowed. Similarly, those who did not have formal education had poorer companionship support than those who had completed primary school education and those who had completed secondary school education or above.

To examine the relationship between social support and the perceived well-being of the stroke survivors, Pearson's correlation was performed. Different types of support functions were compared with the subjects' functional status (Barthel Index); depressive mood (CES-D) and life satisfaction, respectively. The findings show that there is negative correlation between emotional support and depressive mood ($r=-0.2$, $p=0.036$). This means that those who received better emotional support demonstrated a lesser level of depressive mood. However, no significant correlation was found between the other types of support functions and other dependent variables, functional status and life satisfaction.

6.5.2 Structural aspect

Support network

Based on the concept of support specificity described in Chapter Two, the structural aspect of support was examined, based on six stroke-related support needs circumstances. The subjects were asked to think about whether there was someone who might provide help in case of needful situations, for example, when they wanted to express their personal feelings to someone; when they needed help for specific tasks (transportation, household work, assistance in activities of daily living); when they needed information or advice; when they needed a companion for leisure activities. In each of the six support needs circumstance, the subjects were asked to name the person(s) whom they thought might help them (perceived support). They were then asked to name the person(s) whom had actually helped them in the past four weeks (actual support). The number of person(s) named by the subjects was calculated. Their relationships with the subject were explored. The size and sources of perceived and actual support networks were then generated for each support needs circumstance. The size of perceived support networks varied from zero to 14, whereas the size of actual support networks varied from zero to 4. The findings suggest that, in general, fewer persons had actually provided support than the number of person thought to be available. More obvious discrepancies between the perceived network size and the actual network size were found in the circumstances of: (1) expression of personal feeling; (2) provision of information and/or advice; (3) companionship for leisure time activities.

Apart from the beneficial effect of social support, the subjects in this study also identified person(s) in their support networks producing negative encounters. Twenty-nine (25.9%) subjects perceived negative interactions among the member(s) in their social network. Among those 29 subjects, 86.6% of them reported that they had an actual encounter with negative interaction among their named member(s) within the past four weeks. The subjects reported three main sources of negative interaction from their social networks, namely, in-laws, sons and nurses. This finding is similar to those of Clinton et al. (1998) who found that the social network and its function may not be always beneficial and positive. Negative interactions such as having arguments, being upset by someone's expression, feelings of being ignored might occur among the network members.

The findings of this study also support the view that social support has a reciprocal relationship among members within the support network. Forty-five (50.9%) subjects reported that they had been helping other members in their social network before the stroke. Their responsibilities included looking after grandchildren, helping with household tasks, helping with the family business, being the breadwinner of the family as well as providing advice and guidance to the young family members. In other words, these subjects used to be the care providers and hence were needed by members of their social support networks before the occurrence of stroke.

Source of support

The subjects were asked to identify the name of persons whom they perceived to be available for support, as well as those from whom they actually received support.

The subjects were then asked to identify their relationship with the person(s) mentioned. Based on the subjects' response, the following categories on sources of support were formulated, including spouse, immediate family (son and daughter), extended family (in-law, grandchild and relatives), friends (colleagues, neighbours, cohabitants), health professional (medical practitioners, nurses, physiotherapists and occupational therapists), paid domestic helpers and non-professional health care providers (health care assistants, ward attendants, home helpers). The sources of perceived and received emotional support and tangible support were mainly from the spouse and the immediate family. The majority of the subjects relied on health professionals for informational support. It was noted that the stroke subjects perceived their nurses as the main source of informational support. Nevertheless, findings indicate that the subjects mainly received informational support from their physiotherapists. In the area of social companionship, friends were the major source of support in both the perceived and actual support categories. Table 6.16 summarises major sources of support for the six stroke-related support needs circumstances. Generally speaking, findings among the subjects in this study show that the spouse is the main perceived and actual source of support in many support needs circumstances. The son is perceived to be available in many support needs situations, but the daughter is the most frequently mentioned source of actual support.

Table 6.16 Summary table of major sources of support in support needs circumstances

	Rank	Private feeling	Positive feedback	Material aid	Physical help	Information	Companionship
Perceived support	1	Son	Son	Son	Spouse	Nurses	Friend
	2	Spouse	Daughter	Daughter	Daughter	Physio-therapists	Spouse
	3	Daughter	Spouse	Spouse	Son	Medical practitioner	Son
Actual Support	1	Spouse	Son	Son	Spouse	Physio-therapists	Friend
	2	Daughter	Daughter	Daughter	Daughter	Medical practitioner	Spouse
	3	Son	Spouse	Spouse	In-laws	Nurses	Daughter

6.6 Conclusion

This chapter presents the demographic characteristics and clinical conditions of the sampled stroke survivors. The perceived well-being among stroke survivors, as well as social support availability and utilisation are also reported. Phase I results show that in relation to the functional status among the stroke survivors, around 80% of the subjects suffered from various degrees of disability that required assistance in activities of daily living. Significant differences in the levels of functional status were found among subjects with different levels of motor and sensory impairment, cranial nerve impairment, ataxia and presence of post-stroke complications. The findings of this study are comparable to findings of other studies, that stroke survivors suffer from various levels of depressive mood. In fact, 69% of the subjects in this study were found to be depressive-prone. The level of depressive mood experienced by the stroke survivors differed among subjects depending on their educational background, the extent of motor impairment and the presence of visual impairment. Those with better emotional support experience a lower level of depressive mood. The findings of life satisfaction among stroke survivors show that the majority of the subjects indicate dissatisfaction with their current physical health status and level of independence in self-care. Those who suffer from cranial nerve impairment, visual impairment and post-stroke complications report less satisfaction with their current life situation.

Regarding social support availability and utilisation, the findings of this study show that among different types of support function, social companionship is the least available type of support. Those who were married were found to have better emotional support, tangible support and social companionship. Pre-morbid place of residence also affected the levels of tangible support. Those who lived with family during the pre-morbid stage were found to have better tangible support than those who lived alone or with unrelated cohabitants. In terms of the structural aspect of social support, findings show that perceived and actual support network size differ. In needful situations, the number of persons perceived to be available is more than the number of persons who actually provide support. The majority of the subjects mainly rely on their spouse and immediate family for emotional and tangible support. Friends were found to be the main source of support for social companionship. The main source of support with regard to health-related information was physiotherapists.

Phase I findings presented in this chapter provide important baseline information for comparison with findings six months after the stroke. Stability or change in findings between Phase I and Phase II as well as predictors for the perceived well-being six months after stroke will be discussed in the next Chapter.

CHAPTER SEVEN

THE RESULTS OF THE PHASE II STUDY

7.1 Introduction

Phase II data collection was conducted between June 1998 and February 1999. There were 95 subjects remaining in the study. Two subjects died before the six month follow up (the mortality rate was 1.8%). Fifteen subjects did not participate in the Phase II interview (the non-participant rate was 13.4%). Comparison was carried out between the drop-out subjects (n=17) and those who remained in the study (n=95). Stability or change in major variables between Phase I findings and Phase II findings will be discussed in the following sections.

7.2 Description of drop-out subjects

Seventeen subjects (15.2%) did not complete Phase II of the study. The drop-out rate in this study was comparable to another recent community-based prospective study by Ho, Chow and Woo (1998). Of these 17 subjects, one died of recurrent stroke and one of breast cancer. Four subjects could not be contacted by telephone to arrange a second phase interview, either because of incorrect telephone numbers (n=2) or their telephone numbers had been installed with a security code (n=2). Five subjects were contacted by telephone but three of them refused to participate. The remaining two agreed to be interviewed at their own home. However, they were too ill to complete the whole interview. Six subjects (35.3%) were not contacted because they were away from Hong Kong during the Phase II period. Their family members or flatmates told the researcher that they had migrated to the Chinese mainland for care and/or treatment. The drop-out rate of this study was 15.2%. Table 7.1 summarises the reasons for the drop-out.

Table 7.1 Reasons for drop-out (N=17)

Reasons for drop-out	n	%
Wrong telephone number	2	11.7
Telephone had security code	2	11.7
Migrated to The Chinese mainland for treatment and care	6	35.3
Refused	3	17.6
Condition deteriorated and could not complete the interview	2	11.7
Died	2	11.7

Migrating to the Chinese mainland was one of the main reasons for drop-out in this study. This was also the major reason for drop-out in a concurrent study on stroke caregivers conducted by the researcher and her colleagues (Sit, Wong, Clinton, Li and Fong, 1999, unpublished data). A possible explanation could be that stroke survivors in Hong Kong have easy access to the Chinese mainland for care and treatment. Compared with the local health care environment, where conventional Western Medicine remains the mainstay in medical care, the Chinese mainland has more alternatives, for example, herbalist medicine and acupuncture. Besides, the living standard in China is relatively lower than that in Hong Kong. The family members of the stroke survivors found it easier and more acceptable to arrange to paid caregivers or relatives to look after the stroke survivors in the Chinese mainland than to arrange for their stroke family members to live in nursing homes (Sit, Wong, Clinton, Li and Fong, 1999, unpublished data).

Subjects in the drop-out group were compared with those who remained in the study. There was no significant difference in demographic characteristics and clinical conditions between the two groups (Tables 7.2 and 7.3). The possible differences in key variables such as social support and the dependent variables (functional status, emotional status and life satisfaction) were also examined. Significant differences were found in emotional status as well as in tangible support between the two groups. As shown in Table 7.4, the drop-out group had a lower mean in tangible support and a higher mean in emotional status than the other groups. This means that the drop-out group had poorer tangible support and indicated a higher level of depressive moods than those who remained in the study.

Table 7.2 Comparison of demographic characteristics between drop-out and non drop-out groups

Demographic characteristics	Subjects remained in the study (N=95)		Subjects dropped out (N=17)		*p*
	n(%)	Mean(SD)	n(%)	Mean(SD)	
Age		67(10.67)		68.1(10.42)	NS
Sex					NS
Male	49(51.6)		9(52.9)		
Female	46(48.4)		8(47.1)		
Marital status					NS
Single	8(8.4)		1(5.9)		
Married	60(63.2)		9(52.9)		
Widowed/separated/divorced	27(28.4)		7(41.2)		
Education level					NS
No formal education	46(48.4)		9(52.9)		
Primary	31(32.6)		6(35.3)		
Secondary	17(17.9)		1(5.9)		
Technical	1(1.1)				
University			1(5.9)		
Occupational status					NS
Unemployed	3(3.2)		1(5.9)		
Retired	49(51.6)		8(47.1)		
Housewife	15(15.8)		4(23.5)		
Unskilled manual labourer	21(22.1)		2(11.8)		
Sedentary	2(2.1)		1(5.9)		
Skilled/technical	5(5.3)		1(5.9)		
Premorbid place of residence					NS
Hostel	3(3.2)				
Home alone	6(6.3)				
Home with flatmate/friend	5(5.3)		2(11.8)		
Home with relatives	1(1.1)		1(5.9)		
Home with family	80(84.2)		14(82.4)		
Migrant					NS
No	77(81.1)		14(82.4)		
Yes	18(18.9)		3(17.6)		

NS=Not significant

Table 7.3 Clinical conditions between the drop-out and non drop-out groups

Characteristics of clinical conditions	Subjects remained in the study (N=95)		Subjects dropped out (N=17)		*p*
	n(%)	Mean(SD)	n(%)	Mean(SD)	
Stroke type					NS
Haemorrahgic	19(20)		1(5.9)		
Ischaemic	76(80)		16(94.1)		
Stroke side					NS
Left	49(51.6)		9(52.9)		
Right	46(48.4)		7(41.2)		
Comorbidity					NS
No	16(16.8)		4(23.5)		
Yes	79(83.2)		13(76.5)		
Complication at T_0					NS
No	89(93.7)		16(94.1)		
Yes	6(6.3)		1(5.9)		

NS=Not significant

Table 7.4 Major variables between drop-out and non drop-out groups

Characteristics of major variables	Subjects remained in the study (N=95) Mean(SD)	Subjects dropped out (N=17) Mean(SD)	*p*
Social support			
Emotional support	25.38(4.21)	25.00(4.50)	NS
Tangible support [a]	13.80(4.65)	10.76(3.75)	P=0.035
Informational support	12.33(3.91)	11.65(3.57)	NS
Social companionship	9.26(2.40)	9.12(3.00)	NS
Functional status (Barthel ADL) Index	13.83(5.99)	11.94(5.40)	NS
Emotional status (CES-D) [b]	21.91(10.17)	27.59(9.77)	P=0.013
Life satisfaction	32.10(5.97)	30.00(6.35)	NS

[a] t=2.13, df=110, p=0.035

[b] t=-2.54, df=108, p=0.013

NS=Not significant

7.3 The stroke survivors' perceived well-being six months after the stroke

7.3.1 Functional status 6 months after the stroke

Functional status was assessed using the Barthel ADL Index 6 months after the stroke in the subjects' current living environments, the majority being in their own homes. Ninety five subjects were interviewed. By adopting Wade's classification (1987) as mentioned in Chapter Six, 55 subjects (57.9%) obtained the maximum score which means that these subjects had achieved full independence in basic activities of daily living (Barthel score of 20). There were 13 subjects (13.7%) classified as very severely disabled, severely disabled or moderately disabled (Barthel score of 14 or below) indicating that this group of subjects had moderate or severe limitations requiring considerable help or total dependent on others in activities of daily living six months after the stroke.

Among individual ADL items, as shown in Table 7.5, over 90% of the subjects were independent in bowel control, grooming and feeding. When compared with the Phase I findings, the three most obvious improved ADL items were walking stairs (increased by 143.6%), bathing (increased by 100%) and attending to toilet needs (increased by 74.8%).

Table 7.5 Comparing ADL items between Phase I and six months later

Independence in ADL	Phase I (T_0) N (%) (N=112)	Six months later (T_1) N (%) (N=95)	Percentage of increase
Bowel			
Incontinent	14 (12.5)	3 (3.2)	
Occasional accident	9 (8.0)	0 (0)	
Continent	89 (79.5)	92 (96.8)	21.30%
Bladder			
Incontinent	16 (14.3)	2 (2.1)	
Occasional accident	10 (8.9)	8 (8.4)	
Continent	86 (76.8)	85 (89.5)	16.50%
Grooming			
Needs help with personal care	31 (27.7)	4 (4.2)	
Independent	81 (72.3)	91 (95.8)	32.50%
Toilet use			
Dependent	32 (28.6)	4 (4.2)	
Needs some help	24 (21.4)	8 (8.4)	
Independent	56 (50.0)	83 (87.4)	74.80%
Feeding			
Unable	7 (6.3)	1 (1.1)	
Needs help	16 (14.3)	6 (6.3)	
Independent	89 (79.5)	88 (92.6)	16.40%
Transfer			
Unable	8 (7.1)	0 (0)	
Needs major help	29 (25.9)	4 (4.2)	
Needs minor help	9 (8.0)	9 (9.5)	
Independent	66 (58.9)	82 (86.3)	46.50%
Mobility			
Immobile	23 (20.5)	0 (0)	
Wheel chair independent	13 (11.6)	6 (6.3)	
Walks with help of one person	17 (15.2)	6 (6.3)	
Independent	59 (52.7)	83 (87.4)	65.80%
Dressing			
Dependent	18 (16.1)	2 (2.1)	
Needs help	34 (30.4)	20 (21.1)	
Independent	60 (53.6)	73 (76.8)	43.30%
Stairs			
Unable	72 (64.3)	19 (20.0)	
Needs help	10 (8.9)	14 (14.7)	
Independent	30 (26.8)	62 (65.3)	143.60%
Bathing			
Dependent	76 (67.9)	34 (35.8)	
Independent	36 (32.1)	61 (64.2)	100%

Table 7.6 compared the Phase I data (T_0) with data for six months later (T_1). The number of subjects who obtained a full score on the Barthel Index (BI) increased from 23.2% at Phase I to 57.9% six months later. Those who scored 14 or below (the moderately disabled to very severely disabled group) dropped from 44% at Phase I to 13.6% six months after the stroke. The mean BI score improved from 13.54 (SD=5.92) at Phase I to 17.99 (SD=3.48) at Phase II. To test the difference in ADL performance between the sampled stroke survivors of Phase I and Phase II, the Wilcoxon Signed-Rank test was performed. Results show that there was a significant difference between the subjects' ADL performances at Phase I and at Phase II ($Z=6.683$, $p<0.001$). Table 7.7 compares the Barthel ADL mean scores at Phase I (T_0) and Phase II (T_1).

Table 7.6 Functional status at Phase I and Phase II

Barthel Index	Phase I (T_0) (N=112)		Phase II (T_1) (N=95)	
	n	%	n	%
Very severely disabled	10	8.9		1.1
Severely disabled	24	21.4	4	4.2
Moderately disabled	16	14.3	8	8.4
Mildly disabled	36	32.1	27	28.4
Independent	26	23.2	55	57.9
Total	112	100.0	95	100.0

Table 7.7 Comparison of the BI score between Phase I and Phase II

Barthel ADL Index	Phase I (T_0) (N=112)	Phase II (T_1) (N=95)	*p*
Mean	13.54	17.99	<0.001
Standard Deviation	5.92	3.48	
Minimum	0	3	
Maximum	20	20	

Z=6.683, p<0.001

7.3.2 Emotional status 6 months after the stroke

Among the 95 subjects who remained in the study, nearly 70% showed an improvement in their emotional status. As shown in Table 7.8, the mean of the Centre of Epidemiology Studies-Depression scale (CES-D) was 18.2 (SD=10.39). In comparing the findings for Phase I and Phase II, the Wilcoxon Signed-Rank test was performed. A significant difference was found (Z=-3.687, p<0.001) between Phase I and Phase II findings indicating that the subjects' emotional status had improved significantly six months after the stroke.

Table 7.8 Comparison of the CES-D score between Phase I and Phase II

CES-D	Phase I (T_0) (N=112)	Phase II (T_1) (N=95)	*p*
Mean	22.8	18.2	<0.001
Standard Deviation	10.28	10.39	
Minimum	3	5	
Maximum	48	45	

Z=-3.687, p<0.001

7.3.3 Life satisfaction six months after the stroke

As shown in Table 7.9, six months after the stroke, the subjects' average life satisfaction score was 33.9 (SD=6.58) which was higher than that at Phase I. To test the difference between life satisfaction in Phase I and Phase II, the Wilcoxon Signed-Rank test was performed. Results showed a significant difference in life satisfaction between Phase I and Phase II (Z=2.76, p=0.006).

Table 7.9 Comparison of life satisfaction at Phase I and six months after stoke

Life satisfaction	Phase I (T_0) (N=110)	Phase II (T_1) (N=95)	*p*
Mean	31.78	33.9	0.006
Standard Deviation	6.04	6.58	
Minimum	19	20	
Maximum	48	47	

Z=2.76, p=0.006

Similar to Phase I findings, the majority of the subjects indicated their satisfaction on respect and recognition from others. The three most frequently reported aspects of dissatisfaction at Phase II included: the ability to resume their premorbid role, the opportunity for participating in leisure activities and the amount of freedom to do things one wants to do. Table 7.10 compares the most frequently reported aspects of satisfaction and dissatisfaction between Phase I and Phase II.

Table 7.10 Comparison of the satisfied and dissatisfied aspects of life satisfaction between Phase I and Phase II

Life satisfactions	Rank	Phase I (T_0)	Phase II (T_1)
satisfied aspects	1	Recognition from others	Respect from others
	2	Respect from others	Recognition from others
	3	The amount of time to do things one wants to do	The amount of time to do things one wants to do
	1	Current physical health	Resuming premorbid role
dissatisfied aspects	2	Resuming premorbid role	Opportunities for leisure activities
	3	Independence in self care	Amount of freedom to do things one wants to do

7.3.4 Participation in social activities in the first six months after stroke

In Phase I interviews, the subjects were asked to identify premorbid social/leisure activities in which they had participated regularly. The subjects were then asked how frequently they participated in those activities. In Phase II interviews, subject were interviewed with a similar approach, but this time the questions referred to their current status. Their answers were classified into five categories:

Very regularly (These were activities done every day, even if this was just for a few minutes);

Regularly (These were activities done once or more every week but not every day);

Occasionally (These were activities carried out monthly or twice monthly);

Infrequently (These were activities rarely done); and

Never (These were activities which the subject never did or no longer participated in)

More than 80% of the stroke survivors indicated that watching TV or going for a morning walk were almost every day activities. Around 66.3% of the stroke survivors indicated that most of the day they were just sitting and doing nothing.

Compared with the premorbid state, social/leisure activities six months after the stroke tended to be more homebound. Even though small scale shopping at local stores and markets was the sixth most commonly performed activity mentioned by the subjects, more than 50% of the stroke survivors indicated that local shopping was done only once or twice a month.

In terms of social contact, the majority of the subjects (62%) enjoyed Yum Cha (having "dim sum" in the Chinese restaurants) regularly before their stroke. Such activity was only performed occasionally six months after the stroke. Phase II findings showed that around 70% of the subjects made phone calls to their friends once or twice a week regularly. Some subjects indicated that they had exchanged telephone numbers with fellow patients whom they had met during their hospital stay. Occasionally they would call and chat about each other's progress.

In regard to the formal services provided in the community such as centres for the elderly, nearly 80% of the subjects indicated that they had never attended these centres before their stroke. Nevertheless, elderly centre attendance increased by nearly 10% six months later at Phase II. Most of the sampled subjects attended these centres for blood pressure measurement and health check once or twice a month.

For those stroke survivors who were aged below 60 (N=19 at Phase I, N=16 at Phase II), there were 15 (78.9%) subjects participated in paid work at their premorbid state. However, there was a 76% drop in the employment status six months after the stroke. Only 3 (18.8%) subjects continued to work. Among these three, only one subject continued with his previous occupation. The other two changed their job or worked on a part-time basis.

The four most regular activities before and six months after the stroke are compared in Table 7.11.

Table 7.11 Comparison of four most regular activities at premorbid state and six months after stroke

Most regularly participated activities (Before stroke)	Rank	Most regularly participated activities (6 months after stroke)	Rank
Watching TV	1	Watching TV	1
Local shopping	2	Morning walk	2
Going somewhere using public transport	3	Just sitting, doing nothing	3
Going Yum Cha	4	Chatting with friends on telephone	4

7.4 Social support six months after the stroke

Previous studies have indicated that there are gender differences in social support after the hospitalisation period. Chi-square test was performed to examine the association between sexes and places of residence at six months after the stroke. No significant association was found (X^2=3.02, df=1, p=0.082). Mann-Whitney U tests were performed to examine differences in sexes in the four types of support function at six months after the stroke. Results showed no difference between men and women in emotional support, tangible support, informational support and social companionship at six months after the stroke.

In regard to the functional aspects of social support, the findings six months after the stroke were comparable with the Phase I findings, where social companionship had the lowest mean. This suggested that the stroke survivors had the least support in having a companion for leisure and /or social activities in the first six months after stroke. The four types of social support were compared between Phase I and Phase II. As shown in Table 7.12, when examining individual types of social support function, the mean scores on tangible support, informational support and social companionship were increased. On the other hand, the mean score of emotional support was decreased. That means the stroke survivors received less emotional support six months after the stroke than in the earlier stage of their illnesses. To test the difference between social support availability at Phase I and Phase II, Wilcoxon Signed-Rank tests were performed. The results show that there are significant differences between the findings at Phase I and Phase II in two types of support functions, namely, emotional support (Z=-3.036, p=0.002) and informational support (Z=2.614, p=0.03). Stroke survivors had poorer emotional support and better informational support six months after the stroke.

Table 7.12 Social support at Phase I and six months later

Social support	Phase I (T_0) Mean (SD)[a]	6 months later (T_1) Mean (SD)[b]	*P*
Emotional support	25.32(4.24)	23.82(4.04)	Z=-3.036, p=0.002
Tangible support	13.33(4.64)	14.42(3.31)	NS
Informational support	12.23(3.86)	13.22(2.99)	Z=2.164, p=0.03
Social companionship	9.24(2.48)	9.65(2.55)	NS

[a] N=110 • Two missing data from one of the items in the tangible support section. Two subjects expressed that the question was not applicable to them since they had not encountered problems with money that required help from others even for a small amount. Therefore, these two cases were excluded from inferential analysis in this section.

[b] N=95

NS= not significant

Despite there was significant increases in informational support in Phase II findings, descriptive analysis showed that the content of information received by the stroke survivors was similar between Phase I and Phase II (Table 7.13). This suggests that the stroke survivors received more or less the same information in the first six months after the stroke, even after the stroke survivors had returned to community living.

Table 7.13 Content of information received by the stroke survivors at Phase I and Phase II

Informational support	**Rank**	**Phase I (T_0)**	**Phase II(T_1)**
Most frequently received informational support	1.	Self-care in ADLs	Individual's stroke recovery progress
	2.	Information about stroke in general	Self-care in ADLs
	3.	Individual's stroke recovery progress	Information about stroke in general
Least frequently received informational support	1.	Information about stroke support group	Information about stroke support group
	2.	Where to seek help in emergency situation	Where to seek help in emergency situation
	3.	Community services available to stroke survivors	Community services available to stroke survivors

In regard to the structural aspects of support six months after stroke, the total perceived available support network size ranged from zero to 4. This range was much lower than that at Phase I, where the perceived available network size ranged from zero to 14. Unlike the Phase I findings, the perceived support network size reported at Phase II was similar to that of the actual support network size. Negative interaction within the network members still persisted for some (18%) of the stroke survivors.

Similar to the Phase I findings, the major sources of support six months after the stroke came from the stroke survivors' immediate family and health professionals. The stroke survivors mainly relied on their spouses, sons and daughters for a variety of support, including emotional support, tangible support and social companionship. Apart from the immediate family, about 25% of the stroke survivors reported that they had expressed their personal feelings with other stroke survivors whom they had met during their hospital stay. Also, paid domestic helpers, domicilllary home helpers, and community health nurses also played a role in providing tangible support (physical assistance) and therapeutic nursing care six months after the stroke. In terms of informational support, for a majority of the subjects, medical practitioners were perceived to be the first choice for information or advice. However, they did not obtain much information from the physicians because of a brief consultation period for a visit. Most of the stroke survivors turned to their sons for information. For some sampled subjects, other choices for information or advice included their physiotherapists and community health nurses. It was also noted that some subjects reported that they had made informal contact with their fellow patients for an exchange of advice and information.

In brief, from Phase II data, it was noted that the major sources of support for the stroke survivors were provided by the spouse and immediate family. Health professionals, especially medical practitioners, physiotherapists and community health nurses played an important role in providing informational support. The findings also indicate that fellow stroke survivors may have a role in emotional and informational support.

The majority of the subjects were satisfied with the support received in the four weeks prior to the Phase II interview. Between 16% and 33% of subjects thought that emotional support was not needed because they believed that things had to be handled by themselves. Others could not understand their situations. In addition, some indicated that they did not need others' sympathy. On the other hand, about 22% of the subjects said that they would prefer to have more opportunity to talk about their personal feelings. About 10% of the subjects indicated that they needed more encouragement and praise to get them going.

More than 70% of the subjects stated that the tangible support received was about right, in particular, in the aspects of material aids as well as physical help and assistance. In term of financial support, 24% of subjects indicated that the support was inadequate.

Although previous statistical results showed that the level of informational support had significantly increased, when compared with that at Phase I, informational support remained the type of support with which they were most dissatisfied. About 42% of the subjects expressed that they wanted a lot more information specifically on their own current health status and recovery progress. The need for culturally specific dietary advice was another element highlighted by the subjects. In particular, the advice on herbal soups that could reduce blood pressure and prevent recurrence of stroke. About 50% of the subjects indicated that they wanted to know their chances of returning to normal and when that would happen. Another 20% of the subjects asked for advice on complementary medicine, because the current treatment was getting nowhere. Compared with the satisfaction on informational support six months ago, there was about a 12% increase in the needs for informational support at Phase II.

Although the social companionship mean score at Phase II remained the lowest among the four types of support functions, 63% of the subject were satisfied with the level of social companionship received. There were 34% of the subjects expressing that companions for social and leisure activities were insufficient. These subjects indicated that if they had someone to accompany them, they would like to go for social outings or visiting relatives. About 73% of the subjects had been helping other family member before the stroke, such as looking after their spouse, taking care of their grandchildren and helping with shopkeeping. In the Phase I (T_0) findings, for those who had been offering help to others before the stroke, a majority of the subjects were happy with the way they had helped others. The same questions were asked at Phase II (T_1). A majority of the subjects was no longer helping others because of the stroke. Yet, about 45% of the subjects said that they believed they were able and would like to have more opportunities to help others.

To summarise, informational support was one of the areas that a higher percentage of subjects found inadequate. Other inadequate areas included social companionship for leisure activities; tangible support in terms of financial assistance, as well as the opportunity of expressing one's private feelings.

7.5 Predictors of well-beings of the stroke survivors

Two-stage least-squares regression (2SLS) was used to determine the variables predicting perspectives of perceived well-being, namely, functional status, emotional status and life satisfaction. The perspective of participation in social activities was not examined in the regression analysis, because the components were described for the purpose of comparing lifestyle activities in the pre-morbid state and six months later.

Two-stage least squares was considered because it is an important regression technique for models in which one or more of the predictor variables is thought to be correlated with the error term. Using functional status as an illustration, it is generally agreed that the extent of motor impairment and tangible support (providing adaptive aids to facilitate self-care) predict independence in activities of daily living (ADL independence). However, because of complex interrelationships among the dependent variable (ADL independence), tangible support and ADL independence may work in either direction. While it is true that ADL independence depends on the provision of adaptive aids, it is also true that the provision of adaptive aids depends on the severity of ADL dependence – stroke survivors with a better functional recovery need lesser adaptive aids to facilitate self-care.

Variables not included in the model (for instance, a stroke survivor's motivation to become independent in self-care) enhance the stroke survivor's commitment in the rehabilitation regime which leads to improving the ADL performance. The improvement in functional recovery further reduces the need for tangible support. In this case, it is the theoretical errors that are correlated with the predictor (tangible support). Such a correlation violates the assumptions of regression analysis and leads to inconsistent coefficients in the model.

The feedback relationship between tangible support and ADL independence models for such data is usually afflicted with correlated errors. That is, the errors in the equation are correlated with one or more of the predictor variables. If this is the case, estimates made with the ordinary least squares regression are inconsistent. The ordinary least square (OLS) is not appropriate to use in this complex model.

2SLS on the other hand considers two types of variables. The endogenous variable is a variable that is causally dependent on the other variables(s) in the model. In the feedback situation, each of the variables in the feedback relationship is endogenous. Instrumental variables are variables that are not influenced by other variables in the model but they do influence the predictor variables. Instrumental variables may or may not be a part of the equation, but they are free of causal influence from any of the variables in the equation. Figure 7.1 is an example for illustrating the relationship between outcome variable, endogenous variables, instrumental variables and errors.

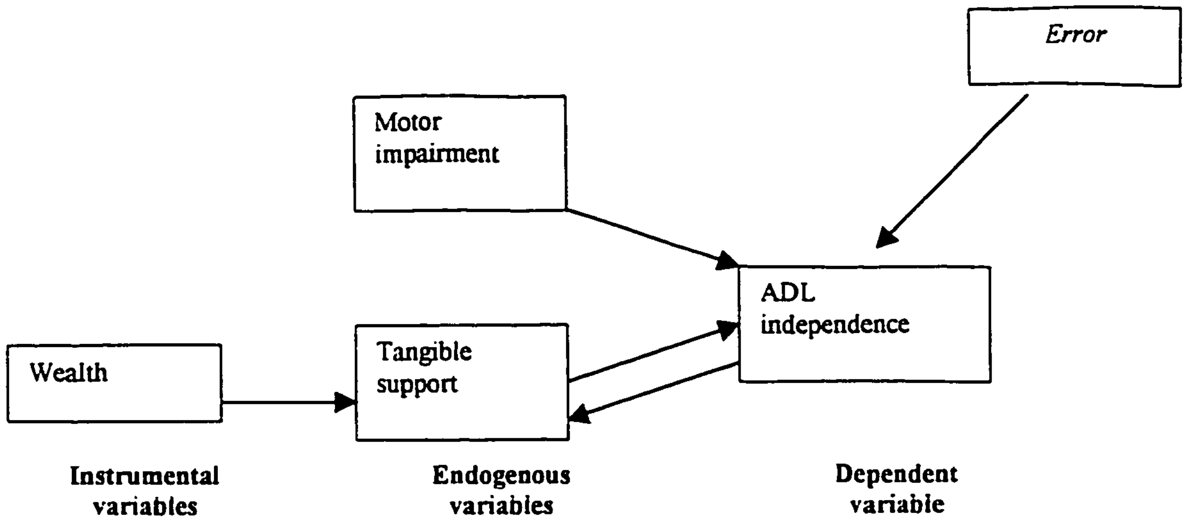

Figure 7.1 Example illustrating endogenous and instrumental variables

7.5.1 Results

Both similarities and differences were found in variables predicting perspectives of well-being six months after stroke. The following paragraphs report findings on predictive models in the perceived well-being of stroke survivors six months after the stroke in the perspective of functional status, emotional status and life satisfaction respectively. Two stage least squares regression was employed for analysis. All residuals of the three predictive models were checked for normality with the Kolmogorov-Smirnov test. The results supported the hypothesis that residuals of variables were normally distributed. 2SLS regression was performed to identify the predictive variables for the three dependent variables respectively (i.e. functional status, emotional status and life satisfaction six months after stroke).

7.5.2 Functional perspective

Functional status six month after the stroke (measured by Barthel Index) was used as the dependent variable. Age and sex adjusted 2SLS regressions were performed until all insignificant variables were excluded. The final model showed six variables explaining 57% (Adjusted R^2) of the variance in ADL independence. The predictors of functional perspectives of well-being were the improvement in social companionship in the six months after stroke (β=0.225, p=0.003), age (β=-0.217, p=0.004), visual impairment (β=-0.146, p=0.049), continence (β=0.279, p=0.003), attendance at medical services (β=-0.221, p=0.003) and Phase I ADL independence (β=0.329, p<0.001) (Table 7.14). In other words, those who did better in their functional status tended to have more social companions, be younger in age, be continent, have no visual impairment, attending medical services less frequently and were more independent in activities of daily living at Phase I. Figure 7.2 illustrates the relationship between predicting variables and functional perspective of well-being six months after stroke.

Table 7.14 Predictors of functional perspectives of well-being six months after stroke

Perspectives	Variables	Standardized β	t	p	Adjusted R^2	F
Functional well-being (at six months after Stroke)	Improvement in social companionship	0.225	3.106	0.003	0.57	20.65*
	Age	-0.217	-2.96	0.004		
	Visual impairment	-0.146	-2.00	0.049		
	Continence	0.279	3.04	0.003		
	Attendance at medical services	-0.222	-3.09	0.003		
	Phase I ADL independence	0.329	3.584	<0.001		

* P < 0.001

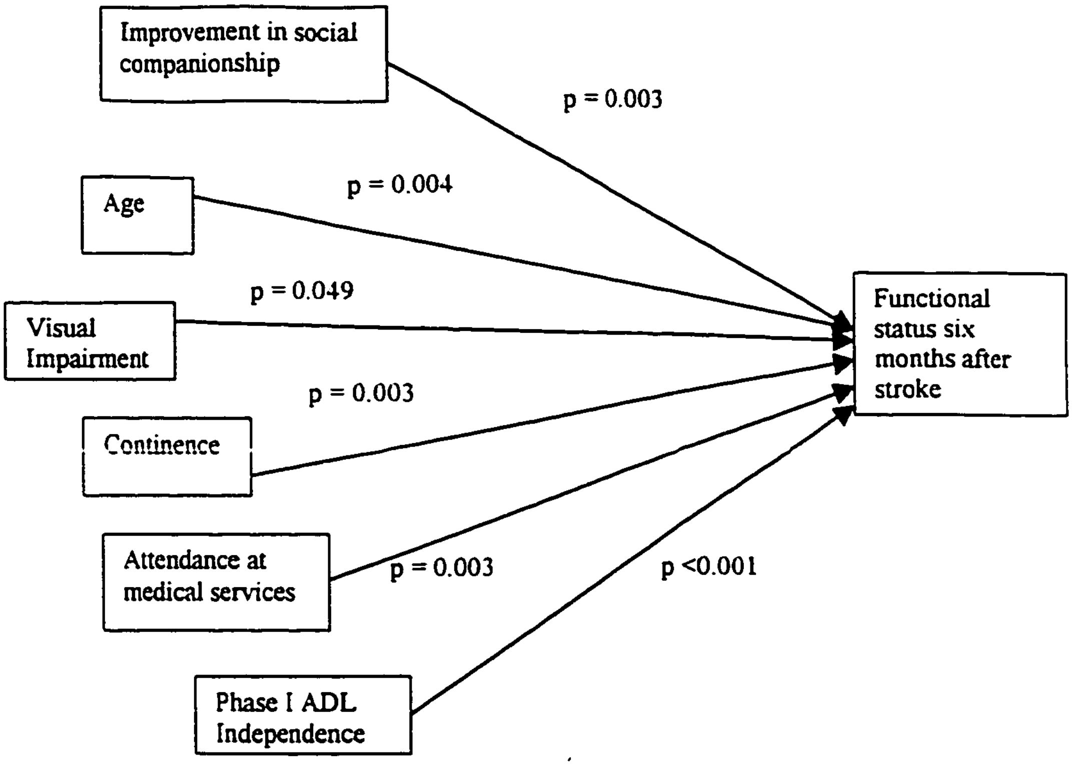

Figure 7.2 Relationship of predicting variables and functional perspective of well-being six months after stroke

7.5.3 Emotional status

Emotional status six months after stroke (measured by CES-D) was used as the dependent variable. Age and sex adjusted 2SLS regression was performed. The final model showed seven variables explaining 55% (Adjusted R^2) of the variance in emotional status. For the purpose of easy interpretation of data, all negative signs indicating positive effect on outcome variables were converted to positive signs. Similarly, all positive signs indicating negative effect on outcome variable were converted to negative signs. The predictors of emotional perspectives of well-being were the improvement in tangible support (β=0.196, p=0.013), social companionship at Phase I (β=0.367, p<0.001), improvement in social companionship in the six months after stroke (β=0.357, p<0.001), premorbid role as a homemaker* (β=-0.269, p<0.001), visual impairment (β=-0.209, p=0.007), comorbidity (β=-0.199, p=0.011) and Phase I emotional status (β=-0.423, p<0.001) (Table 7.15). In other words, those who had a better recovery of emotional status six months after stroke tended to have more social companionship, better tangible support, no visual impairment, less comorbid illnesses and less depressive symptoms reported at Phase I. The findings also noted that for those whose premorbid role was a "housewife*" tended to be more depressed six months after the stroke. Figure 7.3 illustrates the relationship between predicting variables and emotional perspective of well-being six months after the stroke.

Table 7.15 Predictors of emotional perspectives of well-being six months after stroke

Perspectives	Variables	Standardized β	T	p	Adjusted R^2	F
Emotional well-being	Social companionship at Phase I	0.367	4.096	<0.001		
	Improvement in tangible support	0.196	2.539	0.013		
	improvement in social companionship	0.357	3.819	<0.001		
	Premorbid role as homemaker*	-0.269	-3.689	<0.001	0.59	13.01*
	Visual impairment	-0.209	2.752	0.007		
	Comorbidity	-0.199	2.591	0.011		
	Phase I emotional status	-0.423	-5.360	<0.001		

* P<0.001

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*homemaker is a general term used for describing the member in a family, who can be a man or a woman, with the responsibility of taking care of the household chores and looking after other family members.

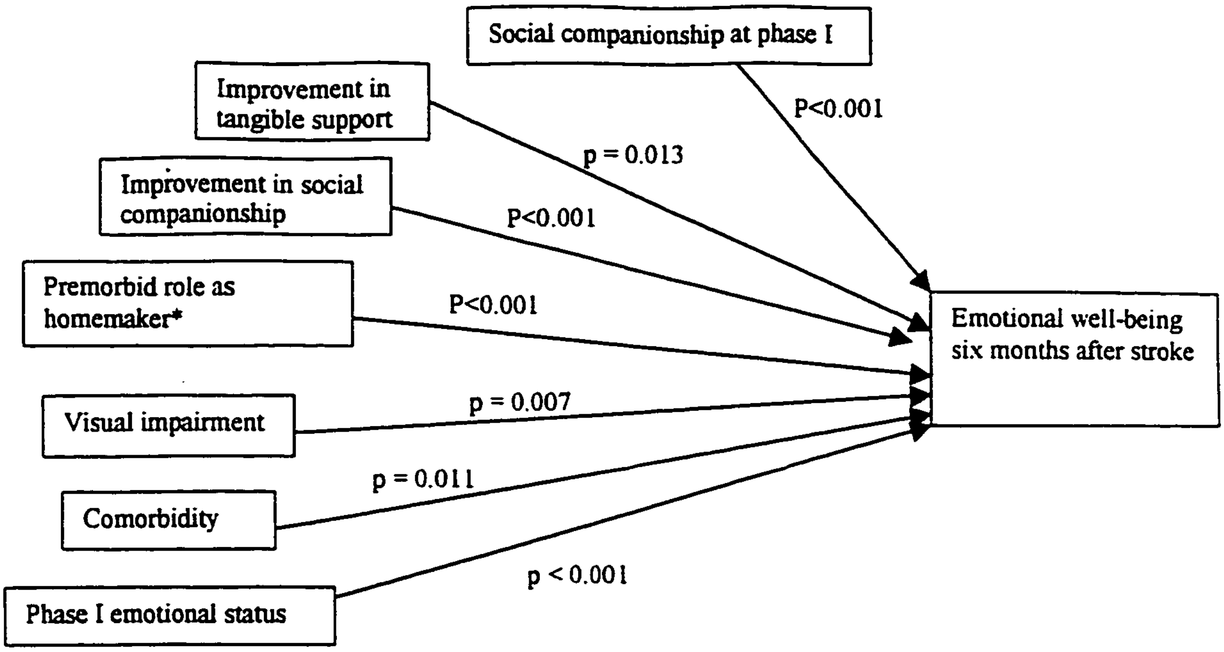

Figure 7.3 Relationship of predicting variables and emotional perspective of well-being six months after stroke

7.5.4 Life satisfaction

Life satisfaction six months after the stroke was used as the dependent variable. The final model showed five variables explaining 37% (Adjusted R^2) of the variance in life satisfaction. The predictors of life satisfaction were social companionship at Phase I (β=0.436, p<0.001), improvement in social companionship in the six months after stroke (β=0.533, p<0.001), premorbid role as homemaker[*](β=-0.237, p=0.006), visual impairment (β=-0.269, p=0.003), comorbidity (β=0.199, p=0.011) and attendance for medical service (β=-0.373, p<0.001) (Table 7.16). In other words, those who were more satisfied with their current situation six months after stroke

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[*] homemaker is a general term used for describing the member in a family, who can be a man or a woman, with the responsibility of taking care of the household chores and looking after other family members.

tended to have better social companionship, no visual impairment, less frequent in attending medical service. Similar to the findings in emotional status, those who used to be a homemaker* before their stroke tended to be less satisfied six months after stroke. Figure 7.4 illustrate the relationship of predicting variable and life satisfaction six months after stroke.

Table 7.16 Predictors of life satisfaction six months after the stroke

Perspectives	Variables	Standardized β	t	p	Adjusted R^2	F
Life satisfaction	Social companionship at Phase I	0.436	4.250	<0.001		
	improvement in social companionship	0.533	5.163	<0.001		
	Premorbid role as homemaker*	-0.237	-2.795	0.006	0.37	11.49*
	Visual impairment	-0.269	-3.122	0.003		
	Attendance at medical services	-0.373	-4.341	<0.001		

* $p < 0.001$

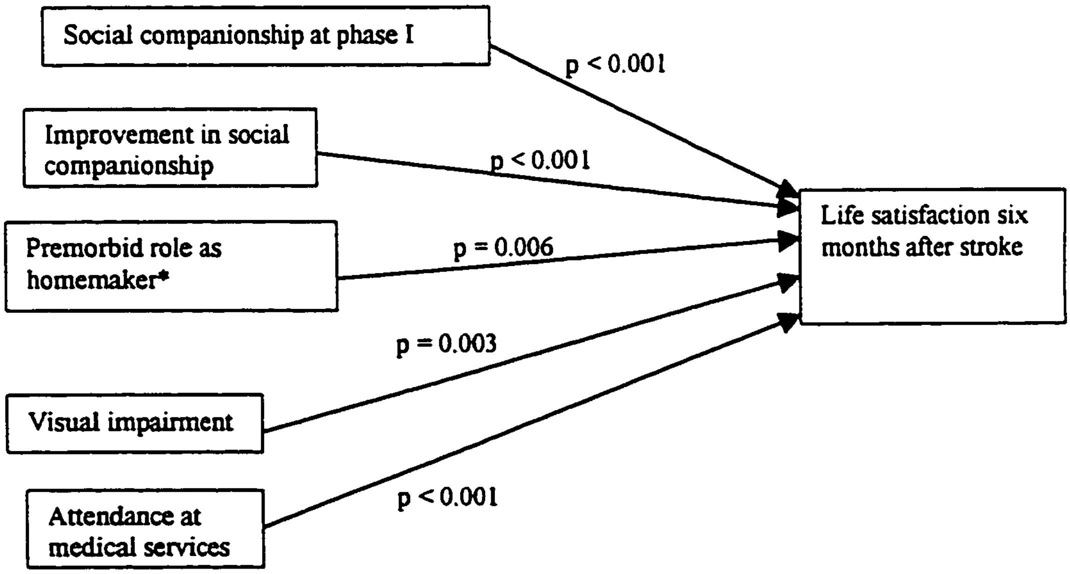

Figure 7.4 Relationship of predicting variable and life satisfaction six months after the stroke

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* homemaker is a general term used for describing the member in a family, who can be a man or a woman, with the responsibility of taking care of the household chores and looking after other family members.

To summarise, three models of the stroke survivors' perceived well-being at six months after the stroke were developed. They are functional well-being, emotional well-being and life satisfaction. In consideration of the inter-relationships among variables, for example, the possibility of covariating effects among the three dependent variables; the bi-directional effects between the dependent variables and the predicting variables; as well as the possibility of correlated errors (the errors in the equation being correlated with one or more of the predicting variables), 2SLS regression analysis were performed. Table 7.17 summarises the significant predicting variable for the three perspectives of perceived well-being at six months after the stroke.

Table 7.17 Summary table on predicting factors on the perceived well-being six months after the stroke

	Functional	Emotional	Life Satisfaction
Improvement in social companionship	*	**	**
Age#	*		
Visual Impairment#	*	*	*
Continence	*		
Attendance at medical services#	*		**
Phase I ADL Independence	**		
Social companionship at Phase I		**	**
Improvement in tangible support		*	
Premorbid role as homemaker*#		**	*
Comorbidity#		*	
Phase I emotional status		**	

*: $p < 0.05$ **: $p < 0.001$

# denotes negative predictor

From Table 7.17, two common predicting variables were identified. Social companionship was found to be the common positive predictor, whereas visual impairment was found to be the common negative predictor of the three perspectives of well-being at six months after the stroke.

7.6 Conclusion

This chapter presented the perceived well-being of the stroke survivors six months after stroke. Comparisons of perceived well-being immediately after the acute phase of stroke (Phase I) and six months later (Phase II) were performed. The perceived well-being of the sampled subjects six months after stroke in terms of functional status, emotional status and life satisfaction is improved significantly. Nevertheless, when compared with the pre-morbid status, social aspects of living produce the reverse picture. In particular, the level of participation in leisure-time activities and social outings is reduced and the sampled subjects tend to be housebound six months after stroke.

This chapter also presented the findings of the regression analysis on identifying possible predictors of perceived well-being six months after stroke in the perspectives of functional status, emotional status and life satisfaction. Findings show that social support in the forms of social companionship and tangible support demonstrate a role in the perceived well-being of stroke survivors six months after stroke. Clinical factors such as visual impairment, co-existing illness and incontinence are also important predictors. In examining predicting factors for each of the three perspectives on perceived well-being, two common predicting factors, namely social companionship and visual impairment, are common to all of the three perspectives. Such findings imply that these are important variables that might contribute to the stroke survivors' overall well-being in the first six months of stroke recovery. Both Phase I and Phase II findings warrant further discussion. Explanation and discussion in the context of this study.will be presented in the next chapter.

CHAPTER EIGHT

DISCUSSION

8.1 Introduction

In this Chapter, findings on the sampled stroke survivors will be summarised according to the aims of the study and research questions. The convergent and divergent findings of this study and the relevant studies will be explored and discussed.

The majority (86.3%) of the sampled stroke survivors had returned home six months after the stroke. Others lived in Government subsidised or private nursing homes. Adaptation to live with the physical limitations in community dwelling became one of the major focuses. The findings in this study show no significant association in sexes and places of residence at six months after the stroke. The stroke survivors' perceived well-being; the availability of social support in the first six months after the stroke as well as factors predicting the perceived well-being at six months after the stroke will be discussed.

8.2. Perceived well-being in the first six months after the stroke

In line with the concept of health and the operational definition of well-being identified in the earlier Chapters, stroke survivors' well-being will be discussed in four perspectives, namely, functional perspectives of well-being, emotional perspectives of well-being, participation in social activities and life satisfaction.

8.2.1. Functional perspectives of well-being

Immediately after the acute phase of stroke:

Immediately after the acute phase of stroke (Phase I of the study), 80% of sampled stroke survivors suffered from some degree of functional disability. The extent of the disabling consequence in walking and self-care varied from mild to severe. About 20% of the subjects obtained full scores in the Barthel Index indicating independence in basic activities of daily living. About half of the subjects had moderate to severe disability requiring considerable help or total dependence on others in basic activities of daily living. The most difficult tasks reported in this study were: bathing, attending to toilet needs, walking and walking stairs. The functional status of the subjects was comparable to that in many other relevant studies (for example, Dekker, Drenden & Eisma, 1995; Wilkinson et al., 1997; Duncan et al., 1997; Chang & Mackenzie, 1998). The findings suggest the need for considerable therapeutic and nursing attention to promoting functional recovery for stroke survivors immediately after the acute phase of stroke.

The findings in this study support the findings in previous studies on stroke that no significant differences are found in ADL independence among the subjects of different age groups, sex, as well as type and side of stroke. The extent of neurological impairment resulting from the stroke produces differences in the stroke survivors' functional performance at the initial stage of recovery. Findings from this study show that the stroke survivors, who suffer from hemiplegia or hemiparesis in motor function, paraesthesia in sensory function, cranial nerve impairment and ataxia, performed worse in ADL independence. Similarly, the stroke survivors who suffer from post-stroke complications, such as hemiplegic shoulder pain, urinary tract infection and pneumonia, perform worse in ADL independence. Findings in this study support Ebrahim's (1990) assertion that the presence of neurological impairment and post-stroke complications should be considered when planning interventions for enhancing functional recovery.

At six months after stroke

At six months after the stroke, there was significant improvement in ADL independence among the subjects. More than 50% of the sampled stroke survivors attained full independence in basic activities of daily living. Only around 14% of the subjects remained moderately to severely disabled. Most obviously improved ADL tasks included bathing, attending to toilet needs and walking up and down stairs. This may reflect the effectiveness of therapeutic training on mobility and self-care during the first six months after stroke.

However, health professionals must be cautious in interpreting the results. In particular, the following issues need to be considered:

(1) Standardised ADL scales are thought suitable for monitoring progress in functional recovery after a stroke. Nevertheless, even widely used measures, such as the Barthel Index (BI) (Mahoney and Barthel, 1965), suffer from "ceiling" and "floor" effects that lead the stroke survivors with extreme severity of stroke to either

score at the top or the bottom of the scale, thus reducing the sensitivity to change. As an elaboration, the BI generally sub-divides ADL independence into a three point scale: completely dependent, require assistance and independent. Such classification with patients who require some assistance to perform each ADL task often being grouped together is crude Therefore, the BI is not sensitive to change and is unable to detect the quality and quantity of assistance. In addition, there is a lack of sensitivity in the upper range of ability rendering the "ceiling" effect. This problem was particularly evident in the subjects at six months after stroke. For individuals who obtained the highest possible score (full ADL independence), their functional status varied. As an illustration, among the subjects obtaining the highest score in the BI, their level of mobility differed. Some had returned to their usual self and resumed their pre-morbid level of function while some continued to rely on walking aids and were unable to walk outdoors.

(2) The maximum score in the scale represents full independence in activities of daily living. However such "independence" does not mean that the stroke survivor can live alone in community dwelling. As previously mentioned in Chapter Two, currently used ADL scales, including the Barthel ADL Index, only measure essential survival activities, for example, mobility, continence and feeding. To live with stroke needs more than mere survival skills. In fact, those basic ADL tasks are too superficial and, sometimes, out of context to the reality that stroke survivors have to face in community dwelling. Hence, health professionals also need to be aware of the social aspects of living in the long recovery process after stroke. Participation in social activities will further be discussed in Section 8.2.3.

8.2.2. Emotional perspective of well-being

The reported level of depressive mood in the first six months after the stroke

The present data suggest that the experience of depressive mood after a stroke is common among the subjects. The mean Centre of Epidemiology – Depression (CES-D) score of the stroke survivors immediately after the acute phase of the stroke was 22.77 (SD=10.28). Findings at six months after the stroke showed that nearly 70% of the subjects demonstrated various degrees of improvement in their emotional status. The CES-D mean score reduced to 18.2 (SD=10.39) at six months after stroke. Comparing the CES-D mean score in this study with other relevant studies suggest that the sampled stroke survivors had higher CES-D means, both immediately after the acute phase of stroke and six months later, than those in studies conducted by King (1996) and Duncan et al. (1997). In other words, the stroke survivors in this study had a higher level of depressive mood than those in studies conducted in Western countries. It is suspected that post-stroke emotional adaptation and the experience of depressive mood vary among stroke survivors with different cultural backgrounds.

Comparison of the proportion of depressed stroke survivors in different studies further highlights the variations in the manifestation of depressive mood among the stroke survivors. Using the conventional cut off score at 16 (which was validated in Hong Kong by Chi and Boey, 1994), the percentage of depressed stroke survivors in this study was around 69% immediately after the acute phase of stroke and 48% six months after the stroke. Such a proportion is comparable with a community-based study on stroke conducted in Taiwan (Fuh et al, 1997) and studies conducted by Andersen, Vestergaard, Riis and Lauritzen (1994); and Morris, Raphael and Robinson (1992), where the reported percentages of stroke survivors experiencing post-stroke depressive mood were between 40% and 60%. Nonetheless, the reported percentage of depressed subjects in this study is much higher than those in studies conducted by Morris et al. (1996), Herrmann et al. (1998) and MacHale et al. (1998), where the reported percentage of depressed stroke survivors was between 20% and 37%.

In consideration of the divergent findings among studies, cohort differences and methodological differences between studies need to be examined. In relation to cohort differences, the time interval between stroke episode and depression screening needs to be taken into account. For methodology differences, the following methodological issues may explain the divergent findings. First, there are many methods of assessing post-stroke depression. Some studies adopted the psychiatry guidelines such as the DSMIII, others adopted standardised self-report depression scales. This makes comparison between studies difficult. Second, the selection criteria varied between studies in relation to the duration since stroke onset, previous history of depression, community versus hospital samples and the inclusion/exclusion of aphasic subjects. All these variations in subject selection may affect the result. Third, there is the possibility of misclassification if adopting conventional cut-off level without testing the comparability between cultures and target populations.

Despite the divergent findings in post-stroke depressive mood, it was generally agreed that stroke survivors tend to be more depressive-prone, especially immediately after the acute phase of stroke. The experience of moods and symptoms of depression were thought to be an understandable and inevitable psychological reaction to the life-threatening illness and loss of physical function. Awareness of and attention to emotional consequences after stroke are of prime importance in planning stroke care both at the acute phase of illness and in the rehabilitative phase of care. In addition, it is worthwhile to note that the prevalence of depressive mood among the subjects was similar to that of stroke survivors in Taiwan (Fuh, et al., 1997). Such findings support the suggestion of Kuo (1984) and Ying (1988) that Asians tend to experience a higher level of depressive mood than their Caucasian countparts. These findings further emphasise the importance of more detailed investigations into the nature of and manifestations of depression among Chinese stroke survivors in future studies.

Factors affecting depressive mood

The present data indicate that depressive mood among the stroke survivors is negatively correlated with one's functional status and life satisfaction. Such findings are comparable to the studies in Taiwan (Fuh et al., 1997) that independence in mobility and self-care impacts, to some degree, on one's psychological well-being among Chinese stroke survivors. However, whether post-stroke depressive mood results in poor functional recovery or vice versa is outside the scope of this study. The researcher cannot infer a causal relationship between post-stroke depressive mood and functional recovery from this study.

Factors found to produce differences in the level of post-stroke depressive mood in previous relevant studies were examined. Findings of the present study do not support the findings of Robert, Robinson, Thomas and Price (1982); Robert, Robinson, Bolduc, Thomas and Price (1987), Stern and Bachman (1991) and MacHale, O'Rourke, Wardlaw and Martin (1998) that pathological factors of stroke, including types and sides of stroke, produce differences in the level of post-stroke depressive mood among stroke survivors. There were no significant differences in the level of post-stroke depressive mood between the subjects who suffered from haemorrhagic and ischaemic stroke, nor stroke in the left side or right side of the brain.

The findings of this study are more comparable to findings from House (1987, 1989 and 1990), Wade, Legh-Smith and Hewer (1987), Morris et al. (1992, 1996) and Herrman, Black, Lawrence, Szekely and Szalai (1998) that sociodemographic variables and neurological consequences may affect an individual's level of post-stroke depressive mood. Immediately after the acute phase of stroke, findings in this study revealed that the subjects with better educational backgrounds and emotional support experienced a lower level of post-stroke depressive mood. The subjects with hemiparesis or hemiplegia, on the contralateral side of their body as well as visual impairment experienced a higher level of post-stroke depressive mood. It is suspected that an individual's level of education, as well as the extent of motor and visual impairment might have an effect on the level of depressive mood experienced by a stroke survivor immediately after the acute phase of stroke.

However, readers should interpret the present results with caution. One cannot conclude from the findings of this study that types and sides of stroke do not have any effect in the level of post-stroke depressive mood. The major reason for this is the fact that exclusion of the aphasic and dysphasic stroke survivors may contribute to the absence of differences between types and sides of stroke in the level of post-stroke depressive mood.

To summarise, this study addressed the experience and level of post-stroke depressive mood in the first six months after stroke. Findings from the present data emphasised the need for nurses in the stroke care team to screen for depressive mood immediately after the acute phase of stroke and its persistence in the later stages of the stroke recovery process. Further studies on causal effects of factors relating to post-stroke depression may be explored. A randomised clinical trial on non-pharmacological interventions in post-stroke depression may also be explored in future studies.

8.2.3. Participation in social activities

One of the major aims of rehabilitation is to maximise stroke survivor's function within his/her physical limitations. To regain functional ability in self-care is the beginning of independent living and, therefore, is the most important element in rehabilitation therapies. As stroke recovery progresses, stroke survivors return to their pre-morbid environment, very often their own home. By then, the coping with the social aspects of living becomes another milestone in stroke recovery. However, the majority of the existing scales for assessing stroke survivors are most valuable in the early stages after stroke, where the assessment of basic self-care activities is paramount. When stroke survivors return home, the activities that they need to perform become more complex. Living in community dwellings refers not only to the "higher-order" activities of daily living (such as household tasks and outdoor mobility) but also includes social aspects of living (such as pursuing lifestyle or leisure activities as well as socializing with friends and important others). Nonetheless, a review of previous literature indicates that the available measures for assessing social aspects of living are either inadequate or inappropriate. Social aspects of living are closely related to social facilities and other social cultural factors. Adopting standard instrumental ADL scales or leisure activities scales developed in Western countries is not appropriate to the context of study in Chinese society. Besides, even within one society such as Hong Kong, social and leisure-time activities vary among individuals of different socioeconomic status. This further makes comparison of social aspects of living among individuals inappropriate. As the aim of this study did not include the development of an instrument to assess stroke survivors' participation in social aspects of living, participation in social and leisure activities were assessed by intra-subject comparison between the pre-morbid state and six months after the stroke. Participation in social activities, as defined in Chapter One, will be discussed in the following sections.

Vocational status

The present data supports arguments of other studies that, at six months after the stroke, the stroke survivors' social aspects of living was reduced when comparing with pre-morbid status. This was particularly evident among the stroke survivors who were below the retirement age. There was about an 80% drop in the participation of paid work at six months after stroke. One reason may be related to the economic turmoil in Hong Kong during the phase two data collection period. Other reasons might arise from the fact that employers in the competitive urban city, where efficiency is highly valued, do not enthusiastically welcome persons with disabilities.

Participation in household activities

Participation in household activities reflects one's independent living in community dwelling. During the interview, the subjects were asked what they did and how frequently they did the activities, compared with before the stroke. In order to assess their performance rather than their capabilities, the stroke survivors were reminded that the questions referred to what they actually did, rather than what they thought they could do. Findings of participation in household activities in this study were comparable to those in Lindmark and Hamrin's (1995) study. The stroke-induced impairments and disabilities reduced the stroke survivors' performance in participating in household activities. Three phenomena were highlighted:

First, it was noted that although the stroke survivors showed significant improvement in motor power, muscle strength, mobility and independence in basic activities of daily living, many reported that most of the time they were just sitting at home, doing nothing.

Second, women had a larger reduction in the participation in household activities than men. This can be explained by the fact that, at the pre-morbid state, women tended to participate more with housework before stroke than men in Chinese families.

Third, during the face-to-face interviews in the subjects' home environment, the researcher observed that the stroke survivors tended to be exempted from doing housework. Stroke survivors' responsibilities for performing housework had been taken over by other family members (usually the spouse, daughter/daughter-in-law) or paid domestic servants. Considering the stroke survivors' physical, neurological and functional recovery, many of the exempted light household activities were within the stroke survivors functional ability.

Social and leisure-time activities

When comparing the five most regular activities reported before and after stroke, it was found that there was a shift to more homebound activities at six months after stroke. Many Chinese people socialise by means of going to "Yum Cha" or playing "Mahjong" with family and/or friends. Such activities have decreased at six months after the stroke. Many of the stroke survivors expressed that they still enjoy going to "Yum Cha" which can be done only occasionally, when their family members have time to accompany them. Approximately two thirds of the subjects quit playing "Mahjong" because of visual difficulty or being too "slow and clumsy".

About 80% of the subjects are unable to look after their family children at home as they did before the stroke. Most of the subjects interpret the reduction of interaction and companionship with children as a loss of vitality in their lives.

Present data also show that a morning walk remained one of the most regular activities. Most sampled stroke survivors believe that a morning walk is good for their health, especially walking outdoors, breathing fresh air and performing light exercise. A morning walk in neighbourhood areas also provide an opportunity for the stroke survivors to socialise with friends and neighbours.

Apart from the morning walk, social outings, for instance attending festival events, visiting friends and dining out have become very occasional events and occur only when the stroke survivors have someone who can accompany them. A major difficulty is that most of the stroke survivors do not feel confident with walking independently on busy streets and taking public transportation, such as buses, trams and the underground. Taxis are thought to be the most reliable means of transportation. Yet, hiring a taxi is expensive and might further affect the stroke survivors' financial situation. Most of the stroke survivors report that unless extremely necessary, they prefer to stay at home.

Chatting with friends or relatives on the telephone is another alternative activity among the stroke survivors. Most subjects make and receive regular telephone calls with family, friends and relatives. Some subjects indicated that they occasionally chat with fellow stroke patients, whom they met at the hospital, to check on each other's progress and exchange information.

In summary, from the descriptive findings of social participation of the subjects, some impressions were highlighted. First, neurological recovery and independence in basic activities of daily living did not improve the stroke survivors' social aspects of living after the stroke. Their participation in vocational, social and leisure-time activities remained insufficient. Second, it would appear from this study that more efforts should be allotted to improve the social aspects of living with stroke survivors. This could be done by exploring with the stroke survivors the impact that their disabilities have on their preferred social life and leisure-time activities. With such mutual understanding, the neurological and physical recovery could be integrated with the facilitation of the social and leisure-time activities specific to the individual stroke survivor's preference. This should be done in such a way that the neurological and functional recoveries begin to make sense to the stroke survivors. This helps the stroke survivors rebuild their understanding of their world and their lives after the stroke.

8.2.4. Life satisfaction

The stroke survivors reported a number of ways in which stroke had affected their functional and emotional aspects of well-being. These have been discussed in the previous sections. Accompanying all these changes, the stroke survivors described a decrease in social and leisure-time activities as well as a loss of valued roles that had been embedded in the everyday functions they had previously performed. In examining the stroke survivors' positive appraisal of the current life situation, it was found that the most satisfying aspects both immediately after the acute phase of stroke and six months later were the recognition and respect that the subjects received. It seems that despite the physical manifestations of stroke and the obvious change in body image, stigma is not a significant consequence of stroke among these subjects.

Satisfaction with the current life situation was compared between the time immediately after the acute phase of stroke and six months later. Findings show that there is a significant improvement in life satisfaction in the first six months after stroke. Findings of this study are comparable to those of other cohort studies that stroke survivors' concern did shift from physical and functional aspects of recovery to a more comprehensive sense of recovery as time went on (Kinney & Coyle, 1992; Astrom, Asplund and Astrom, 1992; Dale, 1995; and Pound and Gompertz, 1998). In the Phase I findings, the stroke survivors were dissatisfied with their current health status and their ability in self-care. A possible explanation may be that immediately after the sudden and unexpected occurrence of stroke, the stroke survivors often experience a period of shock, confusion and grief for their loss of ability and function. The stroke survivors also have a high expectation of full recovery, with a psychological denial of a possible residual disability from the stroke. Impatience and dissatisfaction towards the "slow" recovery are understandable. As stroke recovery progressed, most of the stroke survivors returned home. They were back in their familiar pre-morbid environment. Stroke survivors report many restrictions on their lives, with functions which had been automatic. A holistic sense of living becomes a concern. Therefore, when they were interviewed six months later, there was a shift of concern to the psychosocial aspects of life. The inability to fulfil their pre-morbid roles, the lack of opportunity for leisure activities, as well as the loss of autonomy, have become the most dissatisfied aspects in life.

The concern about diminishing social and leisure-time activities has been discussed previously. The concern of role change was particularly obvious in adaptating to life after stroke. Role change or role reversal was one of the most difficult adjustments to make, especially for those who had been the breadwinner of the family and faced premature departure from the workforce after the stroke.

Analysis of the present data also show that life satisfaction is positively correlated with the functional independence and negatively correlated with depressive mood. Nonetheless, one cannot conclude that those with minimal disability better adjust the psychosocial aspect of life. This is because following a crisis or life-threatening illness, some people may re-interpret their lives and re-evaluate the importance of their different life domains. However, such mental adjustment is outside the scope of this study yet an important area for further research.

In summary, findings from this study suggest that the neurological, functional and emotional consequences resulting from stroke often affect the whole person instead of merely one side of the body. After a stroke, the life situation changes in a way that may impact on an individual's holistic sense of well-being. Such impact not only occurs at the initial stage of the illness, but also extends beyond the hospitalisation period to the stage of recovery. To facilitate a more holistic stroke recovery, there is a pressing need for health professionals to recognise the change in life focus throughout the process of stroke recovery. It becomes vital to assist stroke survivors and their families to learn to accept and deal with the residual loss of function and to adapt to the new situation. Innovative strategies are needed to tackle the environmental and social obstacles to help stroke survivors resume social and leisure-time activities, increase social contact as well as to live a meaningful life after stroke. Traditionally, this has been the realm of the occupational therapist, but a wider focus on psychosocial issues might be extended to other members of the rehabilitation team, nurses in particular. In order to achieve a holistic recovery, the social support, resources as well as its change in relation to the illness need to be explored with the stroke survivors.

8.3. Perceived and received social support in the first six months after stroke

Social support was examined according to the three-dimensional construct, namely, functional dimension, structural dimension and satisfaction towards available support. A general impression from the results of this study is that the perception and availability of social support in these subjects were unique. Convergence and divergence of findings will be explored and discussed in the following sections.

8.3.1 Gender differences in social support

Previous studies found that there were gender differences in the availability and utilisation of social support (Chi and Boey, 1994; Ho and Woo, 1994). Findings in

Ho and Woo's study (1994) on the old-old in Hong Kong showed that women had a higher institutionalisation rate. However, the findings in this study did not show a similar picture. There was no significant gender difference in the four types of support received by the stroke survivors in the first six months after the stroke.

Nonetheless, the findings in this study were comparable with findings of other stroke outcome studies that there was no significant association in sexes and places of residence among stroke survivors (Fuh, Liu, Wang, Liu and Wang, 1997; Woo, Yuen, Kay and Nicholls, 1992). These findings may be explained in the context of cultural concepts on family. In spite of the diminishing Chinese kinship relationship, immediate family unit, including spouse, parents and children, remains close and supportive during difficult times. Therefore, it was found in this study and another study on stroke caregivers (Mackenzie, 1994) that husbands took up the caregiving responsibilities when their wives returned home after stroke. In addition, the availability of live-in paid domestic helpers in Hong Kong also explained why gender differences was not found in social support among the stroke survivors. Very often, the paid domestic helpers shared some of the household chores and day-to-day caregiving tasks. This can be considered as an aspect of support to the family caregivers.

8.3.2 Functional dimension and satisfaction with social support

The functional dimension of social support includes four types of support. They are emotional support, tangible support, informational support and social companionship.

Emotional support

Emotional support was the most frequently received support among the four types of support at the Phase I findings, i.e. while the social survivors had just gone through the acute phase of stroke and were in the hospital. However, results at six months after the stroke showed that there was a significant decrease in the level of emotional support received. Such a finding is understandable. At the initial stage, it is generally agreed in our society that for a victim surviving a serious illness and left with a disability, more understanding and support are needed. Sympathy, concern, reassurance and encouragement from a stroke survivor's natural network such as family members, relatives and friends are obvious. Attention from medical, nursing and therapeutic teams during this initial period is also intensive.

At six months after the stroke, the significant decrease in emotional support may be interpreted as follows. First, as time went by, especially when the stroke survivor is discharged from hospital, the impact of the illness on other people from the lay network may not be perceived to be as strong as in the initial stage of the illness. Therefore, care and attention are not as intensive as before. Second is the "face" issue in Chinese culture (Fok, 1994). When rehabilitation therapies stop, the presence of the residual disability is confirmed. Disabling consequences of stroke are perceived as a personal insufficiency and failure, particularly when it is associated with role change or role reversal. Because of the "face" issue, such feelings of personal failure are usually kept within the person and generally not shared with others, except for those who are very intimate (Fok, 1994). Until the acceptance of disability, stroke survivors may choose to distance themselves from friends and relatives.

While many studies conducted in the West have highlighted the importance of emotional support during a stressful situation or at the time of major illness, about one third of the subjects intimated that emotional support was not needed at all. The majority of subjects intimated that emotional support was comforting but not an absolutely necessity. In other words, emotional support was not highly valued among the sampled population. Some justifications from the subjects were highlighted. It was generally agreed, among the subjects, that close family members such as spouse and children did care for and love them and were therefore trusted. Sympathy, reassurance and expressed concern from others could not improve the current situation. However, care and concern expressed in the forms of more direct, hands-on care and assistance in daily living had more practical value. It was also intimated that emotional support in the form of having someone just to be there as well as occasionally providing positive feedback and encouragement were more valued. Nearly 90% of the subjects intimated, at six months after stroke, that when things happen other people may provide assistance, but it was more important that the stroke survivor should face and handle the problem himself / herself.

To summarise, findings from the present data show that emotional support is perceived to be less important when compared with practical help and assistance in activities of daily living. In regard to the source of emotional support, a majority of the subjects claimed that only close members in the network, such as spouse, children or significant others, are valued. Other people's sympathy and reassurance are not perceived to be necessary. In relation to the form of emotional support, having someone to be there and to provide encouragement are perceived to be more useful. Nonetheless, there was a general belief that one should face one's own problem and accept the challenge. The most important person that one could rely on when dealing with stressful events after stroke is the person himself / herself.

Tangible support

Tangible support includes direct, hands-on care, provision of needed material, finance and supplies. In this sample, major forms of tangible support included, but were not limited to, practical day-to-day assistance in activities of daily living, helping out with household tasks, provision of rehabilitation aids and devices for facilitating self-care and mobility, home modifications as well as arrangements for transportation to and from out-patient rehabilitation facilities.

There was a general impression that the subjects were satisfied with the tangible support in the forms of provision of material aids as well as practical help and assistance in the first six months after stroke. However, six months later, about 24% of the subjects intimated that tangible support in the area of financial assistance was inadequate.

Immediately after the acute phase of stroke, while all the subjects were in the rehabilitation hospitals, provision of tangible support was mainly from immediate family and health care providers. At six months after stroke, when most of the subjects had returned home, the sources of tangible support were diverse. The key role in the provision of assistance in activities of daily living and household activities devolved mainly on family members, such as spouse, daughters or daughter in-laws. If the family member could not meet the need for tangible support, external providers, including paid domestic helpers, domiciliary home helpers and community health nurses were incorporated into the care of the stroke survivors. Meal on wheels, help with household chores as well as assistance in activities in daily living such as bathing, were commonly provided by a non-professional carer. Community health nurses mainly provided services such as health education, wound and skin care, monitoring medication compliance as well as changing urinary catheters and nasal gastric tubes and so on. It follows from these findings that to ensure timely supportive services available to those who are in need, especially those who live alone, discharge planning is an important aspects of rehabilitation.

Concerning financial assistance, the sources of financial support in the subjects were from previous own savings, husband and sons. The Government subsidy such as disability allowance, CSSA was also one of the main sources of financial assistance. Most of the subjects were reluctant to ask for financial assistance from friends and relatives. They preferred to seek assistance from social workers.

To summarise, tangible support was generally perceived to be adequately meeting the needs of the subjects, both in Phase I and Phase II of the study, although some proportion of the subjects intimated an inadequacy of financial assistance. Medical practitioners, nurses, therapists and health care assistants play a key role as care providers during the initial stage of illness while the subjects are still hospitalised. At six months after stroke, when most of the subjects have returned home, the stroke survivors mainly rely on their spouse and immediate family for provision of care and assistance. Consistent with other studies, community care for stroke is needed as in many other chronic illnesses. Domiciliary care services and/or paid domestic helpers play a role in supplementing the insufficient support from an individual's natural social network. Community health nursing services also play an important role for those who require continuous medical and nursing attention or supervision.

Informational support

Informational support was the second least frequently received support after social companionship. It was the area of most dissatisfaction reported by the subjects. Provision of information, both Phase I and Phase II of the study, included dietary advice, health education on medication regimen and compliance, reinforcing technique, skill in self-care and information about stroke recovery. In other words, throughout the six months recovery period, types of information provided to the stroke survivors remained more or less the same. Information provided might not match the stroke survivors' needs throughout the course of recovery.

Perception of inadequacy in informational support highlighted three issues that might be important for health professionals both at hospitals and in the community: content of information, approaches of information delivery and opportunities to ask questions.

1. Content of information

As previously discussed in Chapter Two, support need is context-specific and does change from time to time. Nonetheless, the present study show that as stroke survivors' recovery progresses, in particular during the transition from hospital to home, information provided did not match the changing needs. The stroke survivors received similar nature of information during the first six months after the stroke, for example, etiology and pathophysiology of stroke; prevention of complications or recurrence; self-care in basic ADLs as well as stroke recovery progress in general. Information relating to survival skills for community living; problem-solving in day-to-day care at home and access to social services were not covered adequately. Even at six months after the stroke, around 86% to 95% of the stroke survivors still expressed that they had never been told about mutual support groups for stroke survivors; ways to seek help in emergency situations; and ways for access to community or social services available to them.

Therefore, it is not surprising to note that nearly 50% of the stroke survivors indicated that they needed a lot more information. Findings in the open-ended questions showed the stroke survivors' needs for what to be included in the patient education programme. Important themes are summarised as follows:

(a) General information vs. client-centred information

The stroke survivors needed detail explanations on their own current health status, recovery progress and prognosis. Particular concerns included when and how likely they could return to their usual (pre-morbid) self.

(b) Cultural relevant information on health maintenance practice

Comparing with the conventional medical advice on healthy lifestyles and eating habits, the Chinese traditional health maintenance practice received scanty attention in the nurse-led patient education sessions. Ways to maintain the balance between Yin and Yang, the usefulness / harmfulness of using Traditional Chinese Medicine, taking herbal soups, practising Tai Chi or Qi Kong in stroke recovery were infrequently addressed.

(c) Medical-focused information vs. need-focused information

It was not surprising to identify from the present data that patient education tended to emphasise on physical and functional aspects of care and recovery. Such information may be helpful while the stroke survivors were still staying in the hospitals. However, when a stroke survivor had returned home, skills and knowledge for community living became more imminent. Individual need for support in home care varies, problem-solving skills and information provision must be relevant to individual circumstances.

(d) Availability and access to community services.

Insufficient information on community services was reflected by the stroke survivors' concern for where and how to seek help in urgent situations. The availability of services supporting community care was frequently introduced to stroke survivors through pamphlets or promotion posters. However, the effectiveness of written information without further explanations is questioned.

2. Approaches of information delivery

Effective ways in information delivery also need to be explored. Individual stroke survivor's education background, severity of disabilities, physical strengths, concentration span and motivation all need to be taken into account. The findings of this study highlighted two areas of concern.

(a) Group session vs. individual consultation

Current approach to health education was conducted by nurses or nurse specialists in 1-2 hour small group sessions during the hospitalisation period. Patients with stroke were grouped to attend these patient education sessions. The benefits included cost-efficiency in operation as well as providing chances for sharing among fellow patients. However, professional input usually dominates the discussion. In addition, group sessions usually cover general issues, opportunity to deal with individual concerns is inadequate.

Therapy sessions, either physical therapy or occupational therapy, are mainly operated on individual basis. Individual teaching and coaching becomes possible. The stroke survivors had more opportunities to interact with the therapists. Therefore, it is not surprising to note that the sampled stroke survivors perceived nurses to be one of the main information providers and yet physical therapists and occupational therapists became the actual source of information support.

As group session and individual consultation can be complementary to each other, hospital nurses, apart from organising small group education sessions, can also include client-centred or need-focused individual consultation in their care plan.

(b) Timing of information provision

Provision of informational support must match the individual's learning readiness. In the Phase I interview, i.e. immediately after the acute phase of stroke, around 50% of the subjects did not have a particular concern or questions about their own health and progress. There were about 16% of the subjects did not want to know additional information beyond what the physicians had told them. Three main reasons were expressed: First, the physicians knew best, they were in good hands. Second, they did not bother to ask as they believed that they would be told when the time became appropriate. Third, the subjects were still in denial regarding the disability resulting from stroke. For these stroke survivors, information provision might not be received and retained. Therefore, health education and information provision should begin with the assessment of clients' needs and readiness to learn.

In addition, findings from the Phase II data showed that most of the stroke survivors did not have questions until they returned to their home environment. Information support can be provided via telephone consultation services so that day-to-day problems encountered by the stroke survivors or their family can be dealt with effectively. Information provision on home care and community living after the hospitalisation period is important.

3. Opportunity for asking questions and dialogue

Health professionals have long been accustomed to take the expert role. Very often patients are told or instructed with what the experts believe they should know. It is not uncommon to notice that during health education sessions experts provide information and patients listen. Such practice may be appropriate at the initial stage of illness, when patients do not have much experience of and knowledge about the illness and treatment plan. As recovery progresses, in particular when they are discharged from hospital, patients may have specific concerns or encounter specific problems that might be very individualised. Opportunity to ask questions and to dialogue with the health professionals becomes more important. In addition, apart from health professionals, mutual support between stroke survivors may also be explored. Discussion and advice from someone whom they had encountered and who had gone through similar problems may be more convincing and cost-effective.

The source of information was mainly from health professionals during the hospitalisation period. It was interesting to note that subjects perceived physicians and nurses as information providers, yet therapists, physiotherapists and occupational therapists, turned out to be the most frequent information providers. This might be due to the longer period of contact between stroke survivors and therapists during therapeutic treatment sessions. At six months after stroke, the majority of subjects still perceived medical practitioners to be the first choice for seeking information. If physicians were not available, other alternatives included sons, therapists and nurses. Some subjects reported that they had sought information and advice from fellow patients whom they met during hospitalisation. However, it was noted that a higher percentage of the stroke survivors reported the inadequacy of informational support from health professionals at six months after stroke. The main reason identified was the short interaction time during medical follow-up, leading to less opportunity to dialogue with medical practitioners.

To summarise, the present data show that informational support was perceived to be inadequate. Information needs to be more individualised and relevant to the stroke survivor's stage of recovery and needs. Although informational support is mainly supplied by health professionals, lay persons such as family members and fellow stroke survivors also play a role in informational support. To be more cost-effective in fulfilling the needs of stroke survivors, appropriate content and timing of information provision, as well as opportunity to develop dialogue between health professionals and stroke survivors, should be considered.

Social companionship

Social companionship refers to having someone around and spending time together for social and leisure-time activities. Such contact is mutual and is not viewed as an obligation. Social companionship may serve as another form of emotional support, that signifies a caring which sustains a sense of affiliation and attachment.

Present data indicated that social companionship achieved the lowest level (mean) among the four types of support. The perceived number of companions was significantly less than the actual number. This meant that social companionship was the least available type of support among the subjects. Although the frequency of companion support improved in Phase II of the study, compared with the Phase I findings, about one-third of the subjects indicated that companionship for social and leisure activities was inadequate at six months after stroke. This might be due to the fact that the reduction in physical mobility after stroke together with the environmental obstacles, resulted in the activities of stroke survivors tending to be homebound. Physical and functional disabilities reduced the stroke survivors' opportunity for participating in social and leisure-time activities. Another reason for the reduction in social companionship may arise from the fact that caregivers were too focused on the tangible aspects of care and support on health related issues, so that the need for resuming leisure-time activities seemed to be underestimated and even neglected.

At six months after stroke, the proportion of the subjects who continued to have contact with friends and relatives other than a spouse or children was significantly reduced. However, the ties with immediate family seemed to remain unchanged. Among other reasons, reduced contact with friends or acquaintances could be due to the difficulties with respect to transportation and/or change in vocational status such as being unemployed or taking early retirement after stroke.

Regarding the maintenance of reciprocal support relationships, more than two-thirds of subjects, who used to help out with other family members before the stroke, indicated that they believed they were still able to help and would like to have more opportunity to help others. In particular, family children such as grandchildren were perceived as good companions for many stroke survivors in this study.

Even though social companionship was found to be the least available type of support in this study, approximately 60% of the stroke survivors were satisfied with the current companion support situation. This group of subjects indicated that although they went to "Yum Cha" only occasionally during weekends when their children or spouse had free time, the quality of contact and companionship were valued.

To summarise, present data show that the stroke survivors did perceive social companionship as important, yet, inadequate. Major sources of social companionship shifted from friends and co-workers to spouse and immediate family at six months after stroke. Apart from having companionship for social and leisure-time activities, the stroke survivors also perceived being able to maintain a reciprocal support relationship as another kind of affiliation and attachment. A suggestion from the present findings is that the provision of social support to stroke survivors or people with chronic illnesses has long been focused on emotional and tangible types of support. Social companionship as another form of support that sustains a mutual sense of caring, affiliation and attachment, yet without obligation, demands more emphasis in stroke rehabilitation.

8.3.3. Structural dimension of social support

Previous literature suggests two levels of social support, the cognitive level and behavioural level. Cognitive level of support refers to the perception by an individual of the availability of support by others which may or may not exist. Behavioural level of support refers to the actual support which is received by an individual in various forms such as material, information and practical help when need arises. To present a more comprehensive picture of social support, the cognitive level of social support reflects the sense that one is being loved and cared for, while the behavioural level of social support reflects the experience that one is able to count on others should the need arise. The number of perceived available support providers was compared with the actual support providers according to six context-specific situations. The general impression drawn from the present data show that the actual number of support providers was significantly less than that of the perceived number. In addition, the number of perceived available support providers at six months after stroke was significantly less than that at baseline.

Perceived and actual support

Baseline findings showed that the number of perceived support providers was up to 14. Except for the provision of physical help, the actual number of support providers for situations relevant to emotional and informational aspects and companionship was significantly less than the perceived number of support providers. This was particularly evidenced in "expression of private feelings" and "companion for leisure activities". Subjects were asked to explain why some people mentioned in the perceived support were not included in the actual support. Answers could be summarised into two reasons, either the potential support providers were too busy to be available, or the subject did not want to bother the others as the matters were not important or absolutely necessary.

At six months after the stroke, the number of both perceived and actual support providers decreased to a maximum of 4. Major discrepancies were found in "expression of private feeling" and "provision of advice and information". Reasons for the former were explained in the previous paragraph. The reason for the latter largely arise because after discharge from hospital, the opportunities to contact health professionals are reduced. The brief medical follow-up session did not allow sufficient time to seek advice or information from medical physicians.

Source of support

Sources of perceived and actual support identified by the stroke survivors were diverse including spouse and immediate family, relatives, colleagues, neighbours, friends, paid domestic helpers, non-professional care providers, as well as professional care providers such as physicians, nurses, therapists and social workers. Sources of support were discussed in relation to individual functional aspects of support in the previous sections. However, it is worthwhile to summarise and discuss the major theme in this section.

Findings of the present data further affirm that the source of support is situational-specific. As an illustration, subjects tended to think of and seek help from health care professionals for health-related information and advice. For the direct, hands-on help in day-to-day care as well as emotional support, close family members such as the spouse or children (daughters in particular) would be the priority choice. The findings noted in this study were comparable to findings in either local or international studies that stroke survivors who lived alone and/or were single / widowed had poorer tangible and emotional support (Friedland and McColl, 1992; Ho and Woo, 1994; Clinton et al. 1998). Therefore, it is important to identify this high-risk group in discharge planning.

In terms of social companionship, it was interesting to note that friends were the source of companion at baseline observation. However, at six months after the stroke, the main sources of companionship were the spouse and immediate family. Such findings highlight the significant role of immediate family in the first six months of stroke recovery. Possible reasons were explored earlier. A significant issue needing emphasis here is the importance of involving family members early in the process of care, so as to assist and empower family members to take up this important role in the long recovery process.

Findings from this study further affirm the viewpoint that persons in the support network are not necessarily supportive (Barrera, Sandler and Ramsay, 1981; Clinton et al., 1998). Negative interactions with persons in the support network were identified with about 30% of the subjects immediately after an acute stroke. In-laws, sons and nurses were sources of negative interactions reported by some of the subjects. However, it was noted that the percentage of reported negative interactions reduced at six months after stroke. More than 80% of subjects indicated that their family had been concerned and cared about them. For health care providers, especially discharge planners, it is important to be aware of the fact that social network members and their activities may not always be positive. Social support will never be effective if the recipient does not perceive the provider's support function.
Findings from the present study also suggest that fellow stroke survivors play a role in the social support function and can be mobilised as one of the sources of support. Fellow stroke survivors were named as one of the sources of emotional and informational support. It was expressed that the subjects felt more comfortable to

express their personal feelings toward the disabling consequences after the stroke with someone who was in the same situation. They also intimated that their concern and worry were being listened to and understood. This was better than many sympathetic words from friends or other "normal" individuals. However, the above comment has not been empirically tested in this study. Future research should explore the feasibility and effectiveness of support among stroke survivors.

In summary, the actual number of support providers in one's network was much less than expected. During the transition and adaptation period of recovery in the first six months after stroke, the spouse and immediate family became the most important source for emotional, tangible and companion support. However, for informational support, stroke survivors still heavily relied on health care professionals, medical practitioners in particular. Fellow stroke patients also seemed to play a role in emotional and informational support. Yet, the effectiveness and function of the fellow stroke survivors' support need more empirical evidence. Negative interactions with network members did exist in some of the subjects. Findings of this study, consistent with other findings, emphasises the importance of family support during the early stroke recovery period (Friedlan and McColl, 1992; Chan, Leung, Lai, Yuen and Ng, 1995; MacKenzie, 1998 and Stewart, Doble, Hart, Langille & MacPherson, 1998). Innovative strategies to assist and empower family members to cope with the demand of caregiving are of vital importance.

8.4. Predictors of perceived well-being at six months after stroke

Perceived well-being of the stroke survivors has been discussed in four perspectives, namely functional status, emotional status, life satisfaction and participation in social activities. As social participation did not involve mathematical calculation and analysis, the present information only describes and compares individual stroke survivors' participation in social aspects of living before stroke and six months after. Therefore, social participation was not included in the regression analysis. Predictors for the former three perspectives of well-being will be discussed respectively. Common predictors to all three perspectives of well-being will be highlighted and discussed.

8.4.1. Factors predicting functional perspective of well-being

Clinical factors

Consistent with many stroke-related studies, clinical factors predicted functional well-being at the six months after stroke (Brandstater and Basmajian, 1987; Ebrahim, 1994). Visual impairment, one of the neurological impairments resulting from stroke, had a significant negative correlation with functional well-being among the stroke survivors. Continence, which was another significant predictor found in this study to influence stroke survivors' functional well-being.

Consistent with previous findings, baseline functional status (ADL independence), was found to be a strong predictor for the functional perspectives of well-being at six months after stroke. This may provide a reference point for the estimation of rehabilitation potential. Such information can also be used to identify the high-risk subjects that might need more attention in the therapeutic activities in the recovery process.

Demographic factor

Age also had a significant negative correlation with functional well-being at six months after stroke. This finding is consistent with findings in previous stroke studies and studies on the elderly (Ebrahim, 1994; Chang and MacKenzie, 1998). However, age being a negative predictor to functional status should be interpreted with caution. Without comparison with a reference group, one cannot draw the conclusion as to whether this negative correlation between age and functional status is due to the aging effect on the functional level in general, or is an association between age and stroke recovery.

Social support factors

Improvement in social companionship during the first six months recovery period was found to be a significant predictor of functional well-being at six months after stroke in these subjects. Such a finding has not been addressed in other literature. The researcher speculates that social companionship has several functions. (1). At the initial stage of recovery, namely, immediately after the stroke survivors returned home, a companion at home also provides the supervision and guiding function for self-care. (2). With the presence of someone around, stroke survivors may be more confident in attempting basic self-care, such as going to the toilet and bathing as well as "higher-order" activities, such as walking outdoors, participating in social activities.

Unlike other findings, tangible support is not a predictor for functional well-being in the present data. This may be due to the differences in the degrees of functional disabilities among subjects between Phase I and Phase II. The majority of the stroke survivors had mild to moderate disabilities that may not need extensive assistance.

In summary, the conclusion could be drawn from the findings that the stroke survivors have better functional well-being if an individual is continent and younger in age, has improved social companionship since the illness and does not have visual impairment as a result of stroke.

8.4.2. Factors predicting emotional well-being and life satisfaction

The psychosocial aspect of recovery was assessed by the emotional perspective of well-being and life satisfaction. As some common predictors were identified in both perspectives, discussions on emotional well-being and life satisfaction were grouped together as follows:

Clinical factors

Present data supports the suggestion that a person's physical status has significant impact upon the person's psychosocial status. Visual impairment was found to be a negative predictor that contributed to the variance in emotional well-being and life satisfaction. Comorbidity also had a negative correlation with emotional well-being. The presence of co-existing illness, such as hypertension, hypercholesterolaemia and diabetes mellitus was found to significantly influence the psychosocial aspects of well-being. It was particular true for stroke survivors who had been living in the fear of stroke recurrence.

Social support factors

Social support in the form of tangible support was found to be a significant predictor contributing to the variance in emotional well-being at six months after stroke. Similarly, social companionship was found to be a significant predictor for both emotional well-being and life satisfaction. In other words, a higher level of psychosocial well-being was related to more practical help and assistance, and a higher level of companionship to leisure activities. As mentioned previously, tangible support, in the form of provision of material aid, practical help such as financial assistance, was observable and able to meet the need of stroke survivors if needs arise, whereas social companionship provide a sense of affiliation and attachment. However, it was noted that emotional support, which was considered as one of the important elements of social support in many previous findings (Hill, 1991;

Ragsdale, Yarbrough and Lasher, 1993; Clinton et al. 1998) , had no significant influence on the emotional perspective of well-being nor upon life satisfaction. Findings on social support factors in this study, to a certain degree, differed from previous findings in Western countries. Divergence of findings in this aspect will be explored and discussed in a later section (section 8.4.3).

Demographic factors

It was noted that the demographic characteristic of being a "housewife" before the stroke was a significant predictor for the psychosocial aspect of recovery. The term "housewife" is used for describing the member in a family, who can be a man or a woman, with the responsibility of taking care of the household chores and looking after other family members. Findings in this study show that being a "housewife" had negative correlation with emotional well-being and life satisfaction at six months after stroke. The researcher attempted to explain the issue according to the local situation as follows:

First, unlike those who participate in paid work, a "housewife" does not have sick leave. Once the stroke survivor returns home, there is a sense of taking up his/her usual role and responsibility to take care of the family and look after the household chores. However, the stroke survivors returning home are often faced with one difficult task after another. Previously these were once easily done. Inability or clumsiness in performing even simple household tasks, such as washing dishes and doing laundry may create a new type of loss that further arouses the stroke survivor's sense of burden and uselessness.

Second, people often reported many restrictions on their lives after stroke. More important were the meanings that these restrictions held for them. For a "housewife", the inability to do household tasks causes not simply frustration because the cooking does not get done, but there is a loss of territory. For stroke survivors who have been "housewives" for years, the household is a domain where they have power and control. It is an area in which they have exercised their skills and caring, which in turn increased a sense of pride and recognition. The disability resulting from stroke has taken all these away. The stroke survivors may have no choice but to sink deep into a sense of insufficiency and despair.

Third, the most difficult adjustment to make is role change. The inability to toilet, feed or bathe oneself is not enthusiastically received in our society. For a female stroke survivor who used to be the housewife, if the husband or son is taking up the caregiving role, she has to deal with the personal and cultural meaning of role reversal. This is because the wife's role in a typical Chinese family is to take care of the husband and nurture the children. Loss of physical function, loss of contribution to the family, together with a sense of burden to other family member further diminish a stroke survivor's sense of self-worth and esteem.

8.4.3. Social companionship – a common predictor for functional, emotional well-being and life satisfaction.

Little is known about the role of social support on stroke survivors' in Hong Kong. In the present study, the social support functions and structure were different from previous findings in Western countries. The hypothesis that emotional support has an important role for patients with chronic illnesses and disabilities was not supported from the present data. Instead, results showed that social companionship was found to be a common significant predictor of the perceived well-being in different perspectives: functional well-being, emotional well-being and life satisfaction. Possible explanations can be explored as follows.

Expression of emotions

It is generally agreed that there are cultural differences in emotion expression especially between Oriental and Western cultures. Relatively speaking, Oriental ways of showing emotion are not as expressive as their Western counterparts. In fact, the majority of the subjects noted that significant others' care and concern were understood with "heart" instead of with "words". Very expressive behaviour such as giving a hug, sending a card or verbalisation of sympathy or love may not be appropriate, particularly in traditional Chinese elderly subjects (Fok, 1994; Mok-Suen, 1998).

Social companionship can be interpreted as another form of emotional support. As previously mentioned, companionship provides a sense of affiliation and attachment. The companion does not have a specific duty or obligation. As an illustration, just knowing that someone is around can immediately reduce the sense of loneliness and fear. Companionship of family members for a walk in the park or "Yum Cha" was perceived as a way of showing their care and love to the stroke survivors.

The "face" issue

The "face" issue among Chinese has been addressed in many publications. During hard times, it is not uncommon to find that people isolate their emotions and pretend to be strong and able (Mok-Suen, 1998). This is particularly obvious at difficult times such as a person who has experienced disfigurement and loss of physical function as a result of stroke (Fok, 1994).

Emotional isolation protects one's "face" in a way that others could never know the inside feeling (Fok, 1994). Therefore, it is not surprising to find that many stroke survivors intimated that the opportunity for expressing private feeling was unnecessary. In fact, many subjects felt uncomfortable with others' sympathy and help simply because such actions affirm their loss and attack their dignity and esteem.

In contrast, social companionship can provide help and support in a more subtle and acceptable way. This is because social companionship is mutual and does not involve any obligations. Having someone around can increase a stroke survivor's confidence to walk around in the home. A stroke survivor may feel more comfortable in taking public transport if he/she has someone with them. Companions may make a morning walk more enjoyable as social chatting with others helps one to forget at least temporarily about the present problems. This may explain why social companionship is a significant factor that promotes functional, emotional well-being and life satisfaction.

8.5 Conclusion

The consistent and contrasting findings of this study and the relevant literature were identified and discussed in this chapter. Considerations in the interpretation of results were explored, including the variations in cultural context, research designs, sampling criteria and measuring tools. The subjects' perceived well-being in functional perspective, emotional perspective and life satisfaction at six months after the acute phase of stroke generally improved. Findings of this study further support the notion that social support is situation-specific. The focus of social support changed as the recovery progressed. Social companionship as one of the important predictors of perceived well-being at six months after stroke was also discussed.

CHAPTER NINE

CONCLUSION, IMPLICATIONS AND RECOMMENDATIONS

9.1 Conclusion of the study

Prompted by the continuing transition to community-based stroke care, nurses in Hong Kong are considering the role of social support in stroke recovery and identifying foci for nursing intervention. The aims of this study were to identify a more comprehensive view of the stroke survivors' perceived well-being and to explore whether social support plays a role in the stroke survivors' perceived well-being in the first six months after the acute phase of stroke.

To address the aims of the study, a 6-month prospective design was employed. The subjects recruited to the study were interviewed on two occasions, immediately after the acute phase of stroke (T_0) and six months after recruitment (T_1). Quantitative inquiry methods supplemented with open-ended questions were employed. Structured face-to-face interviews together with neurological assessments were performed to capture the important features and changes during the first six months transitional period following a stroke. All interviews were conducted by either the researcher or one other trained interviewer. To ensure privacy, the stroke survivors were interviewed alone in a place of their choice. With the permission of the hospitals, the subjects' medical records were reviewed for verifying clinical and stroke data.

Upon the completion of the study, a health-oriented picture about stroke recovery was obtained. Factors predicting the perceived well-being of the stroke survivors at six months after the acute phase of stroke were depicted. The following paragraphs summarise the findings:

Perceived well-being of the stroke survivors

The stroke survivors' perceived well-being was reviewed in four perspectives. They were the functional status, emotional status, participation in social activities and life satisfaction. In stroke rehabilitation, there is no golden rule to determine the extent of impairment, symptoms or functional limitation that can be used as a standard outcome indicator. These four perspectives of well-being may reflect a more comprehensive health-oriented outcome indicator that can specifically inform and prioritise aspects of nursing or collaborative interventions for stroke rehabilitation. Both the Phase I and Phase II findings show that the consequences of the stroke affect all perspectives of the stroke survivors' perceived well-being.

Analysis of functional status immediately after the acute phase of stroke revealed that a majority of the stroke survivors suffered from mild to moderate disability subsequent to the neurological impairments. The stroke survivors' functional status improved significantly at six months after the acute phase of stroke. More than 50% of the subjects attained full independence in activities of daily living, for example ambulating, self-care and continence. Such findings demonstrate the effectiveness of therapeutic interventions on functional training during the first six months rehabilitation period.

The stroke survivors' participation in social activities at six months after the stroke was examined. Intra-subject comparison was performed to assess the subjects' participation in advanced activities of daily living and social activities. Comparison was made between pre-morbid status and six months after the acute phase of stroke. Despite the significant improvement in basic ADL independence, findings revealed a general deterioration in participation in social activities, for example participation in paid work, maintaining social contact and leisure-time activities. One of the most frequently performed activities identified during the Phase I interview was "just sitting and doing nothing". This finding persisted even when the analysis was limited to the stroke survivors achieving full independence in basic activities of daily living.

Regarding the emotional status, previous literature demonstrated that depression is highly prevalent in stroke survivors and can significantly diminish an individual's perceived well-being. A locally validated cut-off score for elderly Chinese in Hong Kong (Chi and Boey, 1994) was adopted to assess the prevalence of depressive mood among the stroke survivors. Phase I findings show that the percentage of depressive-prone subjects was high (69%). Although there was significant improvement in the level of post-stroke depressive mood at six months after the acute phase of stroke, the percentage of depressive-prone subjects at Phase II interview was 48%. It was shown that the stroke survivors with motor and visual impairments experienced a higher level of post-stroke depressive mood. In addition to the physiological factors, the subjects with lower educational background and poorer emotional support were found to experience a higher level of depressive mood. Findings from the present data highlight the need for post-stroke depressive mood screening at the initial recovery period for detecting its persistence in the later stage of the recovery process. Assessment data help identify foci for intervention for the 'at risk' group.

With the functional and emotional consequence of the stroke, life satisfaction of the subjects was examined. Findings show significant improvement in life satisfaction at six months after the acute phase of stroke. Comparison between Phase I and Phase II results evidence an important finding that the stroke survivors' life focus changes over the six months period. Immediately after the acute phase of stroke, the subjects were most dissatisfied with their current physical health status and lack of independence in self-care. Six months later, the areas which made them most dissatisfied with life were the inability to resume their pre-morbid role, lack of autonomy and freedom to organise their own activities as well as the lack of opportunity to participate in leisure activities. The findings suggest that throughout the course of recovery, the stroke survivors' life concern may change from physical aspects of living to social aspects of living.

Availability of social support in the first six months after the stroke

The stroke survivors' perceived and actual social support availability were studied. Three dimensions of social support were reviewed. They were functional aspects of support (emotional support, tangible support, informational support and social companionship), structural aspects of support (sources and number of person in the support network) and satisfaction with the support received.

Regarding the structural aspects of support, Phase I finding showed that the perceived support network size was much greater than the actual support network. In other words, immediately after the acute phase of stroke, the subjects thought there were more persons available to help than the actual number of persons who turned up to help them. At six months after the stroke, the subjects' estimation was more realistic and accurate. Sources of support varied according to the circumstances. The subjects relied more on spouse and immediate family members for emotional support and social companionship. Health professionals were the main source of support for informational support. Sources for tangible support varied including their family members, paid helpers as well as health and/or welfare professionals.

Immediately after the acute phase of stroke, findings showed that the most frequently received type of support was emotional support, whereas the least frequently received support was social companionship. The results reported for the perceived well-being imply that the subjects experience a lower level of depressive mood and better life satisfaction if they receive better emotional support during the initial stage of stroke recovery. Comparison was performed between Phase I and Phase II results. The findings reveal changes in social support availability and utilisation in the first six months after stroke. There was a significant reduction in emotional support received by the stroke survivors. Informational support, in contrast, demonstrated a significant increase at six months after the stroke. However, the sources of information support at six months were mainly from lay persons, such as family members or fellow stroke patients.

A review of results on the satisfaction to social support availability and utilisation, supports the notion of "support specificity" identified by Shinn, Lehmann and Wong (1984). Types of support needed, the persons who provide the support and the timing of support provision changed over time and varied according to individual circumstances of need. In other words, the need and provision of social support were context specific. Therefore, if social support provision is to be effective, timing, amount, types and sources of support all need to match with the specific circumstances.

Factors predicting perceived well-being of stroke survivors

Factors predicting the functional and emotional perspectives of well-being and life satisfaction at six months after the acute phase of stroke were analysed.

The functional perspective of well-being was positively predicted by the stroke survivors' functional status (level of ADL independence) at Phase I, continence in urinary and bowel function and the improvement of social companionship during the first six months after the acute phase of stroke. Negative predictors included the stroke survivors' age, presence of visual impairment and frequency in attending medical service.

The level of depressive mood immediately after the acute phase of stroke was found to be one of the important predicting factors on the emotional perspective of well-being six months later. Social support factors, including improvement of tangible support and social companionship during the first six months period, positively predicted the emotional well-being at six months after the acute phase of stroke. Negative predictors included the presence of co-morbid illness and visual impairment. The stroke survivors who, before the stroke, were responsible for managing and looking after the family tended to be more depressed at six months after the stroke.

Life satisfaction at six months after the acute phase of stroke was positively predicted by the improvement of social companionship during the six months period. Negative predictors included the presence of visual impairment and frequency in attending medical services. The stroke survivors who, before the stroke, were responsible for managing and looking after the family tended to be less satisfied with the current life situation at six months after the acute phase of stroke.

Two common predictors of the three perceived well-being perspectives at six months after the acute phase of stroke were identified. They were social companionship (positive predictor) and the presence of visual impairment (negative predictor).

9.2 Implications and recommendations for nursing practice

The nurse's contribution to stroke rehabilitation appears to receive scant attention in the literature and health care services. While nurses contributions to saving and supporting life is highly valued during acute stroke, their contribution to stroke recovery is less recognised compared with the obvious effects of therapies. There is little doubt that nursing is valued, but until the meanings of health and function are interpreted in relation to the "person as a whole" instead of "symptoms", specific nursing contributions seem unlikely to be fully recognised. Therefore, it is time for nurses to critically revisit the concept and goals of rehabilitation within the nursing context and to restructure a specific role in stroke care.

The impression drawn from the findings in this study highlights some issues that might benefit stroke survivors in the course of recovery. These issues will be discussed according to the following: a comprehensive view on stroke recovery; rehabilitation nursing practice revisit; aspects of nursing beyond the hospital boundary, as well as appropriate support to both stroke survivors and their families.

9.2.1. A comprehensive view on stroke recovery

Traditional concepts of health refer to the absence of disease and symptoms. Rehabilitation was once regarded as "the tertiary response to insult or disease", focusing on prevention of complications and preservation of physical function. Rehabilitation specialists devoted their efforts to exploring and testing the neurological mechanisms of recovery and the mechanisms of skill reacquisition after stroke. The mainstay of stroke rehabilitation has been functional recovery for years, until recently.

Generally, it has been agreed that the traditional approach to stroke rehabilitation does not get anywhere, simply because the medical definition of health cannot be applied to those who have chronic illness or disability. Rehabilitation professionals are searching for ways of achieving an optimal level of health in a broader sense, where health refers to a holistic state of physical, mental and social well-being.

Health is viewed as the preserved capacity at the optimal level of physical and psychosocial functions of an individual as a whole. Goldberg (1991) further asserts that these functions of the whole organism performed in its ecological context are much greater than the sum of the operation of its individual parts.

When a comprehensive view of health is adopted in stroke care and practice, the nursing function can be fully recognised. The therapeutic function of nursing in stroke rehabilitation involves an interactive, interpersonal process that nurtures strengths and endurance to assist stroke survivors to attain and maintain an optimal level of health and contentment. This can be achieved by developing, releasing and channeling a stroke survivor's personal and environmental resources for coping with and adapting to the stressful demands during the transitional process after the devastating effects of stroke.

9.2.2. Rehabilitation nursing practice revisit

Rehabilitation nurses are misunderstood to confine their practice only in the convalescence setting. However, when nurses establish plans for care to maintain optimal wellness such as managing complex medical issues, consulting with specialists, providing ongoing patient and family education, setting goals for maximal independence, they are practising rehabilitation principles. Therefore, rehabilitation nursing is a philosophy of care rather than a phase of treatment. The practice of rehabilitation nursing, in fact, is not confined to work settings but applies throughout the whole wellness-illness continuum.

The present study highlights some recommendations for local rehabilitation nursing practice:

(1). A comprehensive view on health and well-being should not remain at concept level, but should apply to practice throughout the stroke recovery process. It is not surprising to find that some stroke survivors suffer depressed mood and lose vitality of life, even though they have gained full independence in attending to self-care and basic activities of daily living. In addition, participation in social and leisure-time activities are found to be lacking even at six months after stroke. The voice of the stroke survivors calling for more opportunities for leisure-time activities was evident. Such findings further support the fact that the needs and expectations of stroke survivors change with the process of recovery. Not until our rehabilitation goals expand to include the psychological well-being and social aspects of living will health and contentment of an individual be achieved.

(2). Rehabilitation nursing traditionally follows the medical model of care. Hospital and community health nurses fulfil a role as care providers. Therapeutic nursing interventions include, but are not limited to, health education, wound and drain care, continence management, attending to nutritional needs as well as monitoring medication compliance. This care provider role has been well accepted by the general public, patients and also among nurses. However, being a direct, hands-on care provider cannot effectively meet the ultimate rehabilitation goal, that is, to assist stroke survivors to regain maximal independence and to live a meaningful life. To achieve this ultimate goal, nursing interventions should strengthen the following two elements: therapeutic communication and coordinating care.

Therapeutic communication is a key component in stroke care to enhance stroke survivors' ability to adjust and adapt to the sequence of effects after stroke, to live with the residual disability and, in the long term, to resume responsibility for their own health. Therapeutic communication can be applied at individual and family level depending on the needs.

Coordinating care is another important element in stroke rehabilitation. There are two levels of coordination: 1. Coordination of services provided by health care professionals in a continuous manner at in-patient settings, outpatient settings and at the client's home or in the community. 2. The second level of coordination involves identification and mobilisation of a stroke survivor's available support system. This refers to the potential support resources from his/her natural social network. The former level of coordination is well recognised and has been in practice for years. The latter level of coordination needs to be explored in a more structured manner. However, due to limited resources, professional care for stroke survivors has to be terminated eventually at some stage of recovery. In the present study, at six months after stroke, about 86% of subjects had completed both inpatient/outpatient rehabilitation sessions and returned home to their family. It is of vital importance to assist stroke survivors to gain competence to resume responsibility for their own life and health. Nurses are in a better position to identify and coordinate support resources from the stroke survivor's natural support network, simply because nurses have more opportunities to meet the patient's family during the hospitalisation period. Identification and mobilisation of family resources as well as supplementation of needed resources that may not be available from patient's natural social network should be included in the discharge planning of all stroke survivors.

(3). Extending care and support to the family members. The present study provided evidence to support the fact that stroke survivors eventually rely on their family for continuous care at six months after stroke. Spouse and immediate family members must be prepared to play the caregiving role. Previous literature demonstrates that family caregivers of people with chronic illness often become the second patient if they cannot cope with this demanding role. Therefore, it is important to include the care of the family caregivers in the nursing care plan.

9.2.3. The needs for care beyond the hospital boundary

Stroke is one of the most common chronic illnesses in Hong Kong and disability is usually the physical end product of stroke. In recent years, medical attention and care at the acute phase of stroke extend to the rehabilitation phase of recovery. However, comparing with the facilities and manpower in hospitals, community services suffer from inadequate resources and recognition. In fact, current resource allocation is out of proportion to the needs and demands from the expanding stroke survivors' population (The Harvard Team, 1999).

Physical function is not fully recovered on the date of hospital discharge. In fact, the realisation of residual disability may not appear until the stroke survivor returns to the familiar pre-morbid environment. Very often, it is not until then that a stroke survivor realises that life will never be the same again. Phase II findings of this study indicates that functional and psychosocial recovery vary from subject to subject. Practical care and support continue to be needed after the stroke survivors are discharged from hospital. Unmet needs may further complicate and delay the recovery process.

Currently, community services such as day care centres, domiciliary services and community health nursing services are available. However, priority is given to the high-risk group, for example, those who live alone or those with medical conditions or complications that require continuing nursing attention and treatment. Apparently, current community services do not meet the increasing demands. Hence, there is a pressing need for the development and expansion of community health services for stroke survivors who are in need. The notion of "nursing by bedside" should be rephrased to "nursing by patient's side". Practising nurses and nurse leaders should inform the Hong Kong SAR Government and policy makers of the needs for community care in stroke management, according to the incidence, prevalence and disability rates as well as service needs in our society.

9.2.4. Integrating social support in nursing practice

It has been increasingly recognised that social support is an important element in health services delivery for people with chronic illnesses. Much literature has demonstrated a variety of concepts and forms of social support. There is no doubt that the personal community in which people are enveloped has a profound impact on their health and morale. This issue has been recognised by policy makers and government officials for years, namely, that without the community's informal support systems, institutional resources and expenditure in professional resources would be overwhelmed. However, it is only very recently that the mobilisation and augmentation of social support have been incorporated into the nursing agenda in providing care to patients with chronic illnesses such as stroke.

With a view to integrating social support in the care of stroke survivors in Hong Kong, the present study highlights the importance of matching the forms of support according to the needs and socio-cultural characteristics of the target population. Needs for different support functions are always context specific and can be changed at different stages of recovery. In addition, social support interventions that are demonstrated to be successful in Western countries may not be appropriate to the Chinese community in Hong Kong. Therefore, prior to the implementation of social support interventions, a comprehensive assessment of a stroke survivor's natural social network and support resources is important, so as to match the support needs. In addition, to better prepare nurses to integrate social support into nursing practice, incorporation of social support issues in the nursing curriculum at undergraduate level may be considered. Specific issues include: the theoretical construct and impacts of social support on the health of the individual, as well as service planning in society as a whole.

Social companionship, which is one important form of social support has been identified as a significant predictor of the functional and emotional perspectives of well-being and life satisfaction in the present study. Social companionship does not involve a hierarchical structure, but is more related to a mutual relationship without obligation. It may be a more acceptable form of help and emotional aid. Nonetheless, whether such finding is unique to these particular stroke survivors or relevant to the Chinese culture needs further empirical evidence in a larger community scale.

Regarding mutual support, the findings of this study indicated that fellow stroke survivors had a role in emotional and informational support. The findings were comparable to relevant local literatures on other chronic illness groups (Mok and Martinson, 2000; Wong, 1997; Tong, 1997; Liu, 1997; Peterkin, 1993; and Chan, Wong, Ho, Ip and Tong, 1992). However, the nature of support identified from the stroke survivors in this study was far from the kind of mutual support or self-help concept identified in those literatures. The supportive relationship among the stroke survivors in this study was more individual-based and less formally organised as compared with the existing operation of mutual support and self-help groups.

The informal contact among the fellow stroke survivors after hospitalisation served certain support functions including emotional sharing, getting information, the exchange of practical tips from each other and the establishment of a sense of affiliation. The findings of this study signaled an important message that the friendship developed among fellow stroke survivors during hospitalisation could be a valuable source to form basis for developing support networks among stroke survivors after they returned home. However, findings showed that the stroke survivors' participation in voluntary or community activities was minimal. Ninety seven percent of the subjects had never participated in mutual support activities. Such findings were consistent with the lack of information provision on the availability of mutual support and self-help group for stroke survivors.

To form a more structured support network, health professionals need to identify ways to nurture and develop the mutual support relationship among stroke survivors and their families. As identified by Mok and Martinsion (2000) and Chan (1992) publicity materials and the mass media are less effective in the promotion of support group or self-help groups. This is because persons with chronic illness have little energy and more mobility obstacles to reach out for group activities that are unfamiliar to them (Chan, 1992). Encouragement from professionals and friends are crucial for persons with chronic illness and disability to take the initiative to participate in such activities. Findings from this study suggested that rehabilitation nurses might expand their roles to a more social oriented perspective in mobilising and developing fellow stroke survivors to play a mutual support role. To this end, the following recommendations are drawn:

At hospital level:

Rehabilitation nurses in the in-patient settings can act as a bridge in the transition from hospital to community. The mutual support culture can be nurtured by means of hospital-based support group for fellow stroke survivors. Nurse-led support group sets up new ties to supplement the existing available resources or create new social bonds at a time of potential isolation from one's network. Friendship and mutual support relationship developed among stroke survivors can be strengthened and sustained beyond the hospitalisation period. Cultivation of mutual support concept may provide basis for more active and independent participation in the community and provide potential membership to the self-help activities.

At community level:

Rehabilitation nurses co-operate and collaborate with community health nurses, social workers, voluntary workers and members of the self-help group. In conjunction with the district-based hospital and social service allocation, self-help group activities could be organised in district-based approach. In other words, activities are organised in neighhourhood areas. Such arrangement may help promote a sense of familiarity and alleviate the concern on travelling and transportation. Building networks among stroke survivors from the same district not only facilitates a sense of cohesiveness, but also enhances effective mobilisation of necessary resources to meet stroke survivors' need.

9.3 Implications and recommendations for future research

The present study provides a basis for further stroke-related research in Hong Kong. Implications and recommendations are discussed as follows:

First, the present study recognises the role and impact of social support in the first six months of stroke recovery process. Findings identify tangible support and social companionship to be significant predictors of perceived well-being among the subjects. The researcher suspects that there is a possibility of incorporating social support as an intervention in future stroke rehabilitation. Further research may examine the possibility and effectiveness of social support intervention for stroke survivors in Hong Kong. For example, the possibility and effectiveness of incorporating social companionship or a mutual support group as an intervention in a stroke rehabilitation programme.

Second, the present study reveals only the tip of the iceberg of stroke recovery. Compared with the long process of recovery, the present study reports only findings in the first six months after stroke. Such information cannot reflect the comprehensive picture of stroke recovery and the change in social support structure and function. If monetary and human resources are available, a prospective study with longer and more frequent follow-ups should be considered. For example, two year follow-up may be considered with data collection immediately after acute phase of stroke, at 6 months, at 12 months and at 24 months. A more comprehensive picture of recovery, particularly psychosocial aspect of recovery, as well as the change in support needs may be revealed.

Third, when comparing findings of the present study with Western literature, it is confirmed that there are cultural variations in the psychosocial aspects of stroke recovery, especially the social aspects of living in the first six months after stroke. The inability to participate in pre-morbid social and leisure-time activities was a concern of the subjects in this study. As social aspects of living are recognised as important elements in stroke recovery, a more culturally specific instrument for measuring social functioning after stroke may be another direction for future studies. Fourth, given the multidisciplinary approach in rehabilitation, further research on stroke rehabilitation may consider collaboration among members of the rehabilitation team, such as the therapists and rehabilitation physician. Also relevant to the integration of social support in stroke care, collaborative research among medical social workers in the community organisations may also be explored.

Fifth, there is an urgent need for the development of a territory-wide stroke data bank in Hong Kong. Currently, the health care delivery system is divided into eight clusters according to the geographical locations. The fragmented development of a stroke data bank in different clusters cannot reflect the whole picture of the stroke population in Hong Kong. Until there is a coordinated effort for the development of a territory-wide stroke data bank, the incidence, prevalence, clinical patterns, disabilities and service needs among the stroke population can never be accurately estimated. After all, resources allocation, service and manpower planning require a reliable database.

Last but not least; the methodological implications and recommendations for future studies include:

1. Compared with the wealth of cross-sectional medical outcome studies, longitudinal studies exploring the process of stroke recovery at different stages seem to be inadequate. Future cohort studies investigating the impact of stroke on

stroke survivors and/or their support network should be explored.

2. Little is known about the experience of recovery in Chinese stroke survivors. As health and illness behaviours occur within a total cultural context, clinical ethnography with in-depth description of sensation and responses of stroke victims may be an alternative to provide a meaningful method of studying the stroke experience. Such information may also provide a basis for development of culturally specific social support and new stroke outcome instruments for further evaluative studies.

3. Regarding the assessment of stroke recovery, there have always been two schools of thought: the objective assessment and subjective interpretation of recovery. Both perspectives are valued. Hence, there may be a need for a more dynamic design so that stroke recovery is assessed by combining various aspects and sources including the rehabilitation professional's objective assessment, stroke survivor's subjective evaluation, caregiver's evaluation, examination of medical records, etc. Such an approach provides a more comprehensive picture on stroke recovery.

9.4 Contribution and value of the present study

With the advancement of medical technology in diagnosis and treatment in the acute stage of stroke, the mortality rate of stroke in Hong Kong is declining. Consequently, there is a dramatic increase in the number of stroke survivors suffering from various degrees of disability who are in need of health and social services. This situation has attracted the attention of the health care providers and policy makers. The urgent needs for in-patient and community rehabilitation services has been addressed by the Hong Kong Government in the "Green Paper: Rehabilitation Policies and Services" in 1992 and the White Paper on "Social Welfare into the 1990's and Beyond" in 1991. However, efficient and effective stroke rehabilitation is not solely determined by where the service is provided or how much manpower is put into the service. Most important is the way health professionals practise rehabilitation for stroke survivors. This follows two questions: first, how good is "good" recovery and, second, what factors contribute to a favourable recovery outcome.

The literature related to stroke is extensive. However, it tends to be dominated by medical perspectives. Currently adopted outcome indicators are over-emphasised on the mortality, impairment, motor and functional recovery, with virtually no attention given to explore how the survivors perceive their own recovery after stroke. This is typically an expert-judged recovery outcome. As the aims of rehabilitation nursing are to deal with alleviation of human suffering and the promotion of optimal state of well-being, it is obvious that physical outcome indicators cannot adequately reflect stroke recovery nor guide nursing interventions. Therefore, this study attempted to explore stroke recovery, in a wider perspective. Hopefully, a more holistic view on stroke recovery can reflect not only the symptom remission and functional recovery but also the psychosocial aspects of living, including emotional well-being, participation in social activities and life satisfaction. The findings may provide information to expand the range of outcome indicators that are more relevant to nursing practice. This can provide a basis for future evaluative studies to investigate the effectiveness of rehabilitation nursing interventions.

Second, the functional and psychosocial consequences after stroke, as well as the long process of recovery place stroke survivors at a high risk of social isolation and dependence. Care of stroke survivors should expand and extend beyond the physical aspects to include facilitating psychosocial adaptation through integration of social support in the process of care. Nurses practise in diverse institutional and community settings and have closer contact with stroke survivors and their network members. Hence, nurses play an important role in enhancing and mobilising their stroke client's support resources. To achieve this, this study attempted to assess social support in different perspectives including the functional aspect, structural aspect and stroke survivors' satisfaction with the availability of support. Findings of this study may enhance understanding of the social support available in stroke survivors' own social network, as well as identify aspects of support that may be lacking. Such findings will have implications for planning cost-effective stroke rehabilitation services and to make sensible use of community resources to facilitate stroke survivors' living in the community.

Third, this study adopted a prospective design to follow stroke survivors during their first six months of recovery. The stability and change in the functional and psychosocial aspects of recovery can be identified. Such findings can inform and encourage health professionals to plan and prioritise treatment, as well as to provide timely interventions at different stages of stroke recovery. Predictive factors that may contribute to perceived well-being among stroke survivors are also discussed.

9.5 In summary

Disability refers to the behavioural end product of disease. Disabilities resulting from stroke can be interpreted as the accumulated constraints imposed by the pathologic process to the cerebral vasculature of a person affecting his/her capacity to function autonomously in daily life. This study explored stroke recovery in a broad sense to include the functional perspectives, emotional perspectives of well-being, participation in social activities, as well as life satisfaction. To facilitate the process of stroke recovery, social support was explored for its impact on the well-being of stroke survivors. It brings to the attention of the nursing profession that the need for social support is context-specific and must be socioculturally acceptable to the recipients throughout the course of stroke recovery. Culturally specific elements of social support in the form of social companionship are highlighted among the selected stroke population. Findings of this study contribute to stroke rehabilitation by providing more comprehensive understanding about stroke recovery, as well as its predicting factors. This information may provide a basis for rehabilitation nurses to plan for intervention to achieve the ultimate goals of stroke rehabilitation, that is, to help stroke survivors adapt to a changed lifestyle, attain the highest possible level of function, and maintain optimal health and contentment. In other words, to live a meaningful life after stroke.

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Appendix 4.1

Interview guide

Code No.: ______

Client information

Date: ______
Client name: ______
HKID No.: ______
Date of birth: ______
Address: ______
______
Telephone: ______

Name of interviewer: ______
Time started: ______
Time finished: ______
Phase 1 ☐
Phase 2 ☐
Area: ______
Code No.: ______

Section I: Demographic Data

D1 Age:	______ (according to HK ID card)
D2 Sex:	(1) Male ☐ (2) Female ☐
D3 Marital status:	(1) Single ☐ (2) Married ☐ (3) Divorced ☐ (4) Widowed ☐ (5) Separated ☐
D4 No. of children:	______
D5 Education level:	(1) No formal education ☐ (2) Primary ☐ (3) Secondary ☐ (4) Technical ☐ (5) College ☐ (6) University ☐
D6 Occupation status: (before stroke)	(1) Unemployed ☐ (2) Retired ☐ (3) Housewife ☐ (4) Unskilled manual labourer ☐ (5) Sedentary ☐ (6) Skilled/Technical ☐ (7) Professional ☐ (8) Student ☐
D7 Financial status:	I. Support (1) Self ☐ (2) Spouse ☐ (3) Children ☐ (4) Parent ☐ II. Allowance (5) DA ☐ (6) HAD ☐ (7) OAA ☐ (8) CSSA ☐
D8 Migrant:	(0) No ☐ (1) Yes ☐ - years in Hong Kong ______
D9 Current place of residence:	In institution: (1) Hostel ☐ (2) Government/subvented C&A Home ☐ (3) Private C&A Home (4) Infirmary ☐ (5) Hospital ☐ At home: (6) Alone ☐ (7) with flatmate/friend (not family relationship) ☐ (8) with relatives ☐ (9) with family ☐
D10 Type of housing:	______
D11 Lift:	(1) Yes ☐ (2) No ☐, specify ______ (3) Other ☐, specify ______
D12 Religion:	(0) No ☐ (1) Yes, specify: ______

Code No.: ______

Section II: Clinical factors

Diagnosis:			
C1 Type:	(1) Haemorrhage ☐	(2) Ischaemic ☐	
C2 Site:	______		
C3 Side:	(1) Left ☐	(2) Right ☐	
C4 Dominant hand:	(1) Left ☐	(2) Right ☐	
Impairment:			
C5/6 Motor	(1) UL ☐	Grade ______	
	(2) LL ☐	Grade ______	
C7 Sensory	(1) Intact ☐	(2) Impaired ☐	(3) Absent ☐
C8 Cranial Nerve	(0) No ☐	(1) Yes ☐	
C9 Visual Field	(0) No ☐	(1) Yes ☐	
C10 Ataxia	(0) No ☐	(1) Yes ☐	
C11 Continence	(1) Continent ☐	(2) Urinary incontinent ☐	
	(3) Bowel incontinent ☐	(4) Double incontinent ☐	
C12 Comorbidity:	(1) Hypertension ☐	(2) D.M. ☐	
	(3) Hyperlipidaemia	(4) others: ______	
C13 Complication:	(0) No ☐	(1) Yes ☐, specify: ______	
C14 Date of onset:	______		
C15 Date of admission to rehabilitation setting:	______		
C16 Date of discharge:	______		

Use of health care services:

During the past 6 months, have you used:

C17 Medical services	Conventional	(0) No ☐	(1) Yes ☐ ______ (times)
	TCM	(0) No ☐	(1) Yes ☐ ______ (times)
C18 Physiotherapy	(0) No ☐	(1) Yes ☐ ______ (times)	
C19 Occupational therapy	(0) No ☐	(1) Yes ☐ ______ (times)	
C20 Community health nursing service	(0) No ☐	(1) Yes ☐ ______ (times)	
C21 Day hospital	(0) No ☐	(1) Yes ☐ ______ (times)	
C22 Day care centre	(0) No ☐	(1) Yes ☐ ______ (times)	
C23 Acupuncture	(0) No ☐	(1) Yes ☐ ______ (times)	
C24 Others, Specify:	______		

Code No ______

Section III: Social Support factors

Social Support for Stroke Survivors

The following questions ask you how frequent these statements happen to you:

A. Emotional support

		Never	Sometimes	Often	Always
A1	People are cool to you	1	2	3	4
A2	People care about you	1	2	3	4
A3	People dislike you	1	2	3	4
A4	When you are lost, people show you the direction	1	2	3	4
A5	People cheer you up when you are unhappy	1	2	3	4
A6	People reassure you when you are down	1	2	3	4
A7	People tell you not to lose courage	1	2	3	4
A8	You feel that you can rely on people around you	1	2	3	4
A9	When things happen, you have to face it	1	2	3	4

Private feelings

A10 If you wanted to talk to someone about things that are very personal and private, who would you talk to? Give me the first names or nickname of the people and their relationship with you.
Probe 1: These people can be your family, relatives, friends, neighbor or people in the hospital.

10a ________
10b ________
10c ________
10d ________

____

____

If no, why?

____

____

____________________________*(go to A12)*

A11 During the last month, which of these people did you actually talk to about things that were personal and private?

11a ________
11b ________
11c ________
11d ________

____

____

Probe: What about those who you mentioned just now but not included here?

____

____

A12 During the last month, how satisfied are you in terms of opportunities to talk to people about your personal and private feelings:

0 ☐ not applicable
1 ☐ not adequate
2 ☐ about right
3 ☐ too much

Positive feedback

A13 Who are the people that you could expect to give you positive feedback?
Probe 1: These people can be your family, relatives, friends, neighbor or people in the hospital.
Probe 2: for example, praise you, tell you that you are doing well, appreciate you idea or give recognition to what you have done.
(These might be people you mentioned before or new people)

____

____

If no, why?

____

____

________________________ *(go to A15)*

13a ________
13b ________
13c ________
13d ________

A14 During the past month, which of these people actually gave you positive feedback?

____

____

Probe: What about those who you mentioned just now but not included here?

____

____

____

14a ________
14b ________
14c
14d

A15 During the past month, how satisfied are you in terms of people giving you positive feedback:

0 ☐ not applicable
1 ☐ not adequate
2 ☐ about right
3 ☐ too much

Negative interactions

A16 Who are the people that you can expect to have some unpleasant disagreements with or people that you can expect to make you angry and upset? These could be new names or names you have listed before.
Probe 1: These people can be your family, relatives, friends, neighbor or people in the hospital.

____

____

(If no, *go to Part B*)

16a
16b
16c
16d

A17 During the past month, which of these people have you actually had some unpleasant disagreements with or have actually made you angry and upset?

____

____

____

17a
17b
17c
17d

B.	**Tangible Support**	Never	Occasionally	Almost as often as I need	As frequently as I need
B1	People lend you small things	1	2	3	4
B2	People lend you small amount of money	1	2	3	4
B3	People help you if you call upon them unexpectedly	1	2	3	4
B4	People help you when you are sick	1	2	3	4
B5	People help you when you have transportation difficulty	1	2	3	4
B6	People accompany you to do specific tasks	1	2	3	4

Material Aid

B7	Who are the people you know that would give you things (money or material) that you need? Probe 1: These people can be your family, relatives, friends, neighbor or people in the hospital.	7a 7b 7c 7d

____

____

If no, why?

____

____

________________________________*(go toB9)*

B8	During the past month, which of these people actually gave you some money or material that you needed?	8a 8b 8c 8d

____

____

Probe: What about people who you mentioned before but not included here?

____

____

____

B9	During the past month, how satisfied are you to the money given to you?	0 ☐ not applicable 1 ☐ not adequate 2 ☐ about right 3 ☐ too much
B10	During the past month how satisfied are you to the material given to you?	0 ☐ not applicable 1 ☐ not adequate 2 ☐ about right 3 ☐ too much

Physical Assistance

B11	Who are the people that you can call on to help you take care of something that you need to do? Probe 1: These people can be your family, relatives, friends, neighbor or people in the hospital. Probe 2: things like driving you somewhere you needed to go, helping you do some work around the house, going to the shop for you, and things like that. (These right be people you mentioned before or new people)	11a 11b 11c 11d

____

____

If no, why?

____

________________________________*(go to B13)*

Code No.: ________

B12	During the past month, which of these people actually helped you do things that you needed to help with? ________ ________ Probe: What about people who you mentioned just now but not included here? ________ ________ ________	12a 12b 12c 12d
B13	During the past month, how satisfied are you in terms of help with things that you needed to do?	0 ☐ not applicable 1 ☐ not adequate 2 ☐ about right 3 ☐ too much

C.	**Informational Support**	Never	Occasionally	Almost as often as I need	As frequently as I need
C1	People give you information on self-care	1	2	3	4
C2	People give you information on where to buy rehabilitation aid	1	2	3	4
C3	People give you information on stroke support group	1	2	3	4
C4	People give you information on available community services after discharge from hospital	1	2	3	4
C5	People give you information about stroke recovery	1	2	3	4
C6	People teach you skills on problem-solving at home environment	1	2	3	4
C7	People tell you your recovery progress	1	2	3	4
C8	People give you advice on where to seek help in needing situation	1	2	3	4
C9	People tell you where to seek financial assistance	1	2	3	4

C10	Who will you go to if a situation come up when you needed some advice? Probe 1: These people can be your family, relatives, friends, neighbor or people in the hospital. Probe 2: For example, about you current health condition, recovery progress or things listed above. ________ ________ If no, why? ________ ________ ________ *(go to C12)*	10a 10b 10c 10d

C11 During the past month, which of these people actually gave you advice?

____

____

Probe: What about people who you mentioned just now but not included here?

____

____

____

11a
11b
11c
11d

C12 During the past month, how satisfied are you in term of the opportunity for people giving you advice when you needed?

0 ☐ not applicable
1 ☐ not adequate
2 ☐ about right
3 ☐ too much

C13 Tell me what kinds of information you want to know?

____

____

____

____

____

____

D. Social Companionship

		Never	Sometimes	Often	Always
D1	People drop in for a (pleasant) visit	1	2	3	4
D2	People call you up and chat to you	1	2	3	4
D3	People join you for social gathering (e.g. dinner, Yum Cha)	1	2	3	4
D4	People invite you to join in leisure activities (e.g. playing mah-jong, eating out)	1	2	3	4

D5 Are there people that you can get together for leisure activities?
Probe 1: These people can be your family, relatives, friends, neighbor or people in the hospital.

____

____

If no, why?

____

____

____________________*(go to D7)*

5a
5b
5c
5d

D6 During the past month, which of these people did you actually get together with for leisure activities?

____

____

Probe: What about people who you mentioned just now but not included here?

____

____

____

6a
6b
6c
6d

D7	During the past month, how satisfied are you in terms of having people to get together for leisure activities?	0 ☐ not applicable 1 ☐ not adequate 2 ☐ about right 3 ☐ too much
D8	Are there any people who need your help, such as: household work, looking after children, giving advice? ________________________ ________________________ If no, why? ________________________ ________________________ ________________(go to D10)	8a 8b 8c 8d
D9	During the past month, did these people actually received your help? ________________________	9a 9b 9c 9d
D10	During the past month, how would you have liked in terms of opportunities to help others?	0 ☐ not applicable 1 ☐ not adequate 2 ☐ about right 3 ☐ too much

Section IV: Functional status

Barthel Index

Item	Score
Bowels 0 = incontinent (or needs to be given enema) 1 = occasional accident (once/week) 2 = continent	
Bladder 0 = incontinent, or catheterized and unable to manage 1 = occasional accident (max once per 24 hours) 2 = continent (for over 7 days)	
Grooming 0 = needs help with personal care 1 = independent face/hair/teeth/shaving (implements provided)	
Toilet use 0 = dependent 1 = needs some help, but can do something alone 2 = independent (on and off, dressing, wiping)	
Feeding 0 = unable 1 = needs help 2 = independent (food provided in reach)	
Transfer 0 = unable, no sitting balance 1 = major help (one or two people, physical), can sit 2 = minor help (verbal or physical) 3 = independent	
Mobility 0 = immobile 1 = wheel chair independent including corners, etc. 2 = walks with help of one person (verbal or physical) 3 = independent (but may use any aid, e.g. stick)	
Dressing 0 = dependent 1 = needs help, but can do about half unaided 2 = independent (including buttons, zips, laces, etc.)	
Stairs 0 = unable 1 = needs help (verbal, physical, carrying aid) 2 = independent up and down	
Bathing 0 = dependent 1 = independent (or in shower)	

Code No.: _______

Section V: Depression

The following questions ask you to describe how frequent you felt or behaved this in the past week:

		Rarely or none of the time (less than 1 day)	Some or a little of the time (1 -2 days)	Occasionally or a moderate amount of time (3 – 4 days)	Most or all of the time (5 – 7 days)
D1	You were bothered by things that usually don't bother you.	0	1	2	3
D2	You did not feel like eating; your appetite was poor.	0	1	2	3
D3	You felt that you could not shake off the blues even with help from your family or friends.	0	1	2	3
D4	You felt that you were just as good as other people.	0	1	2	3
D5	You had trouble keeping your mind on what you were doing.	0	1	2	3
D6	You felt blue.	0	1	2	3
D7	You felt that everything you did was an effort.	0	1	2	3
D8	You felt hopeful about the future.	0	1	2	3
D9	You thought your life had been a failure.	0	1	2	3
D10	You felt fearful.	0	1	2	3
D11	Your sleep was restless.	0	1	2	3
D12	You were happy.	0	1	2	3
D13	You talked less than usual.	0	1	2	3
D14	You felt lonely.	0	1	2	3
D15	People were unfriendly.	0	1	2	3
D16	You enjoyed life.	0	1	2	3
D17	You had crying spells.	0	1	2	3
D18	You felt sad.	0	1	2	3
D19	You felt that people disliked you.	0	1	2	3
D20	You could not get 'going'.	0	1	2	3

Code No.: ______

Section VI: Social participation

Vocational status

(1) Retired before stroke ☐
(2) Took early retirement after stroke ☐
(3) Changed occupation ☐
(4) Returned to previous occupation ☐
(5) Unemployed ☐

Vocat: ____

Family role and responsibility

______
______
______

Social role and responsibility (if any)

______
______
______

Social Activities

Activities that are performed everyday

______
______
______
______
______
______
______
______

Activities that are performed regularly (done once or more every week)

______
______
______
______
______
______
______
______

Activities that are performed at leisure time

______
______
______
______
______
______
______
______

Hobbies / interest

______
______
______
______

Code No _______

Section VII: Life satisfaction

How satisfy are you with the following statements:

		Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied
1	Your current physical health	1	2	3	4	5
2.	Your emotional life	1	2	3	4	5
3.	The respect you get	1	2	3	4	5
4	The recognition you get	1	2	3	4	5
5	Your independence in self care	1	2	3	4	5
6.	The amount of freedom to do things you want to do	1	2	3	4	5
7.	Your opportunities for leisure activities	1	2	3	4	5
8.	The amount of time you have to do the things you want to do	1	2	3	4	5
9.	The ability to return to pre-stroke roles and responsibilities	1	2	3	4	5
10.	Your life as a whole	1	2	3	4	5

- END-

Appendix 4.2

Guideline for testing muscle strengths

Guidelines for testing muscle strength

General instructions:

A. Test muscle strength by asking the person to move actively against gravity first. If there is no problem, then move against your resistance.

B. Muscle strength is graded on a scale of 0-5:

5 – Active movement against full resistance without evident fatigue. This is normal muscle strength.
4 – Active movement against gravity and some resistance
3 – Active movement against gravity
2 – Active movement of the body part with gravity eliminated
1 – A barely detectable flicker or trace of contraction
0 – No muscular contraction detected

(Bates, 1995, p.513).

C If the muscles are too weak to overcome resistance, test them against gravity alone or with gravity eliminated. For example,

a) when the forearm rests in a pronated position, extension at the wrist can be tested against gravity alone.
b) When the forearm is midway between pronation and supination, extension at the wrist can be tested with gravity eliminated.
c) If the person fails to move the body part, watch or feel for weak muscular contraction.

(Bates, 1995, p.512)

D Muscle strengths are compared between left and right side of the person.

Upper limbs

A. Forearm flexion (biceps)
At the elbow, ask the person to pull against your hand.

B. Forearm extension (triceps)
At the elbow, ask the person to push against your hand.

C. Wrist extension
Ask the person to make a fist and resist your downward pull.

D. Grip
Ask the person to squeeze two of your fingers as hard as possible and not let them go.

Lower limbs

A. Hip flexion (iliopsoas)
Placing your hand on the person's thigh and ask the person to raise the thigh against your hand.

B. Hip adduction (adductors)
Place your hands firmly between the person's knees. Ask the person to bring both knees together.

C. Hip abduction (gluteus medius and minimus)
Place your hands firmly on the lateral side of the person's knees. Ask the person to spread both knees against your hands.

D. Hip extension (gluteus maximus)
Have the person push the posterior thigh down against your hand.

E. Knee extension (quadriceps)
Support the knee in flexion and ask the person to straighten the leg against your hand.
Or have the person sat on a chair and ask him/her to straighten the leg against your hand.

F. Knee flexion (hamstrings)
Put the person's leg in knee flexion with the foot resting on the bed. Then tell the person to keep the foot down as you try to straighten the leg.
Or have the person sat on a high chair and ask him/her to bend the knee against your hand.

G. Ankle dorsiflexion
Ask the person to pull his/her foot up against your hand.

H. Ankle plantar flexion at the
Ask the person to push his/her foot down against your hand.

Adapted from: Bates, B. (1993). A guide to physical examination and history taking (6th edition).
Philidelphia: Lippincott

Appendix 4.3

Guidelines for the Barthel Index

The Barthel ADL Index Guidelines:

General instruction:

A. The index is used as a record of *what a person does*, **NOT** as a record of what a person could do. This is to measure ADL performance instead of ADL competence.

a) ADL competence describes the person's current physical capability to carry out the tasks specified. It is usually conducted in a formal test situation.

b) ADL performance reflects the person's actual behaviour in his/her current living environment. It describes the actual, disabling consequences of the disease in WHO terms.

(Smith and Clark, 1995)

B. The main aim of this index is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason. The need for supervision renders the person not independent.

C. A person's performance should be established using the best available evidence. Asking the person himself/herself, health care assistants, nurses, relatives, cohabitants, domestic helpers can be the useful source. Direct observation and common sense are also important. However, direct testing is NOT needed.

D. Usually the performance over the proceeding 24-48 hours is important, but occasionally longer periods will be relevant.

E. Unconscious persons should score '0' throughout, even if not yet incontinent.

F. Use of aids to become independent is accepted.

Bowels

A. If needs enema from caregivers (HCA, nurses, relatives, etc.), then score "incontinent".

B. Accidental incontinence refers to frequency of incontinence not more than once a week.

Bladder

A. Catheterized person: Those who have indwelling catheter and unable to manage catheter care by himself/herself, score "incontinent". However, a catheterized person who can completely manager the catheter, including swabbing, emptying the urinary bag, self-catheterization, then score "continent".

B. Occasional incontinent refers to frequency of incontinence not more than once per 24 hours.

Grooming

A. Independence refers to performance in personal hygiene such as brushing teeth, cleaning and fitting denture, combing hair, shaving, and washing face without help from others.

B. Implements were provided by helper but the person can perform the above without help, score "independent"

C. "Need help with personal care" includes verbal cues, instruction and/or actual physical help.

Toilet use

A. Independence refers to those who can reach toilet/commode, undress sufficiently, clean self, dress and leave the toilet/commode without help.

B. "Need help" refers to can wipe self, and do some other of above, such as need help to undress sufficiently.

Feeding

A. Independence refers to the ability to eat normal food, not only congee, puree. Food cooked and served by others is allowed.

B. If the person cannot hold up the bowl and manipulate chopstick but he/she can manage to eat by himself/herself by using adaptive devices such as with spoon and non-slippery bowl is accepted and scores "independent".

C. "Need help" include those who need others to split food into small portions, removing bones from meat or fish. The person still is able to feed himself/herself.

Transfer

A. Independence refers to the person being able to move from bed to chair/wheelchair and vice versa without any help from others.

B. Minor help refers to those who can perform the above with the help of one ordinary person. It also include needs for verbal cues or supervision for safety in order to perform the above.

C. Major help refers to those who can sit up but need help from others in moving to and from chair/wheelchair and bed. "Help" includes help from one strong or skilled person, or from two ordinary helpers for transferring.

D. Dependent refers to those who do not have sitting balance and needs two persons to lift.

Mobility

A. Independence refers to those who can walk around the ward (while in hospital) or the apartment (while at home), other indoor areas. The use of walking aids of any kind to become independent is accepted.

B. "With help" refers to those who are able to walk but need verbal cues, instruction or physical help from one ordinary helper.

C. "Wheelchair independent": If the person is in wheelchair, he/she must be able to negotiate corners and doors without help.

D. "Immobile" refers to those who are bed ridden

Dressing

A. Independence refers to those who are able to select and put on all clothes and shoes, which may be adapted (for example, modified with zippers, magic tapes).

B. "Half unaided" refers to help with buttons, zips, tiring up shoes laces etc. The person can put on some garments by himself/herself otherwise.

Stairs

A. Independence refers to those who can walk up and down stairs without any help from others. The use of walking aids is acceptable.

B. "Need help" refers to those who need verbal or physical help from others.

Bathing

A. Independence refers to those who can bath or shower without any help or supervision from others. This includes getting in and out of the bathtub or shower, washing and drying the body including the back and feet.

B. "Need help" includes those who perform the above with physical help, verbal cue or supervision from others.

Reference: Collin, C., Wade, D.T., Davies, S. and Horne, V. (1988). The Barthel ADL Index: A reliability study. International Journal of Disability Studies, 10(2), 61-63.

Appendix 4.4

Consent form and explanatory note

Consent Form

I, ______________________________, agree to participate in the research study titled "The impact of social support on perceived well being of stroke survivors" and the purpose of the study was explained by _____________.

I also give permission to the researcher to gain access to my medical record. However, all information and data should be kept anonymous and confidential and will only be used in this research study. I am free to discontinue my participation at any time, and this action will not affect my present or future treatments and services in the hospital.

If there is any question about the research study, I could contact Ms Janet Sit directly. (Office telephone no.: 2766 6549)

Witness' signature: ________________ Patient's signature: ___________________

Date: ______________________________

Please keep this for record:

If you have any question about the research study "The impact of social support on perceived well being of stroke survivors", please contact Ms Janet Sit. (Office telephone no.: 2766 6549; pager: 7322)

Explanatory note

Ms Janet Sit, research student of the Department of Nursing and Health Sciences at The Hong Kong Polytechnic University, is currently conducting a study for her doctoral degree. The title of the study is "The impact of social support on perceived well being of stroke survivors" and you are cordially invited to participate in this study.

The aim of this study is to explore whether social support plays a role in the stroke survivors' perceived well being in the first six months after stroke. The objectives are as follows:

1) To explore the perceived well being of stroke survivors immediately after the acute phase of stroke and six months later.
2) To investigate the stability and change of perceived well being of stroke survivors in the first six months following stroke.
3) To investigate the role of social support in stroke recovery.

The study involves a 60-90 minutes face-to-face interview using questionnaire and a physical test for muscle strength. Also, the interviewers have to gain access to your personal information (i.e. address, contact telephone number) and medical record. However, all information and data will be kept confidential and will only be used in this study. The study involves verbal communication for the interview and physical assessment. No physical harm will be induced throughout the research process.

You are not obligated to participate in this study. If you disagree to participate or do not want to continue the involvement, you are free to stop at any time, and this action will not affect your present or future treatments and services in the hospital.

If you agree to participate in this research study, please sign and date the attached consent form. Thank you very much for your participation.

At any time you want to know the progress of the study or have any question, please feel free to contact Ms Janet Sit (Office telephone no.: 2766 6549; pager 7322).