'KEEPING THE PEACE': MULTIPLE PERSPECTIVES ON DECISION-MAKING FOLLOWING ACUTE STROKE IN CHINA: A CONSTRUCTIVIST GROUNDED THEORY STUDY

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Abstract

Stroke is a major public health concern in China and worldwide due to its significant mortality and long-term morbidity. Following an acute stroke both older people and their family carers often have to make major life decisions in a relatively short period of time. This study explores the nature of the decision-making process between people with stroke, their family carers and professionals in an acute care context in China.

Using a constructivist grounded theory approach data were collected through a combination of methods including semi-structured interviews, participant observation, and documentary analysis. This comprised interview data from 19 people with stroke, 28 family carers and 25 professionals together with 55 periods of observation to ensure 24 hour coverage and an analysis of key policy and practice documents. Constant comparative analysis of the data led to the emergence of two core categories, and their associated social processes, these were 'Keeping the Peace' and 'Making Decisions'.

The core category 'Keeping the Peace' was the most important goal for all three groups of people. This involved both keeping peace of mind for the person with the stroke and keeping peace in relationships between different parties (i.e. inter-professional relationships, inter-familial relationships, patient-carer-professional relationships, and relationships between patient/carer from different families). The core category of 'Making decisions' comprised three major social processes of hiding (permanent hiding, temporary hiding, and tailoring to hide), seeking (searching, watching/comparing, and checking) and sharing (informing, advising, exchanging, and tailoring to explain).

There was a close and dynamic relationship between 'Making Decisions and 'Keeping the Peace' and both were heavily influenced by Chinese culture, especially the traditional Chinese ideal of maintaining harmony. In addition a broad range of other factors also played a part in the overall decision-making process, including: the people who were involved; the types of decisions to be were made; the types of knowledge that was used; environmental factors; medical/treatment related factors; patient-, carer- and professional-related factors.

The grounded theory emerging from this study enhances our understanding of decision-making experiences among older patients with stroke, family carers and

professionals within an acute care setting in China. The insights that emerged are compared with the existing literature, and considered with reference to the broader notions of awareness context theory, partnership working, and relational practice. Implications for practice, education, and policy are considered and recommendations made.

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CONTENTS

LIST OF TABLES

LIST OF DIAGRAMS

LIST OF APPENDICES

CHAPTER 1: INTRODUCTION

Stroke is a major public health concern in China and worldwide due to its significant mortality and long-term morbidity. It is mainly a disease of older people, and can result in physical, psychological and social problems and decreased quality of life. Following an acute stroke both older people and their family carers often have to make major life decisions in a relatively short period of time.

However, existing studies suggest that patients and family carers are often required to make such decisions without an adequate understanding about stroke and its consequences (Hafsteinsdo´ttir et al., 2011; Eames et al., 2010; Mackenzie et al., 2007; Brereton and Nolan, 2002; Wiles et al., 1998). To improve the situation it is suggested that professionals need to actively work with patients and carers, provide timely support, and empower them to make informed decisions in order to better manage the stroke, feel more in control, create positive attitudes towards their disease, receive the best possible care and make a good recovery (Martins, 2009). Therefore, a clear understanding about the experience of decision-making among older patients with stroke, their families, and professionals is needed. This is especially so in China where there has been very little prior work on this topic and where cultural factors may mean that the findings of studies undertaken in the West have limited relevance.

Chinese culture plays an important role in health care decision-making, for example, it is the moral duty of families to make health care decisions for their relatives (Wong and Pang, 2000). Consequently people's experience of decision-making in the area of stroke in China may be different from those in other countries. It is essential to better understand the experiences of decision-making between older people with stroke, their family carers and professionals in the Chinese context. This will potentially help professionals to provide the best possible support and care, promote patients' and family carers' informed decision-making, and enable them to play an active part in their health care (Hoffmann and Cochrane, 2009; Stacey et al., 2008).

This introductory chapter begins by considering my motivation for selecting decision-making with older patients and their families as a focus for my Ph.D. study, and describes some of my previous experiences and understanding about the research topic. It then outlines the subsequent chapters within the thesis providing an overview of the whole thesis.

Personal Motivation for Undertaking the Research

I have been a nurse teacher in the School of Nursing at a Medical University in China since I gained my Bachelor's degree in 1993. In 1995, I undertook a master's programme at the same school which explored baccalaureate nursing students' clinical decision-making ability and the factors influencing it.

During the second year of my master's programme, I studied at the School of Nursing at the University of Ottawa under the supervision of Prof. Margaret Ross, who had particular research interests in Gerontological Nursing. She took me to visit and work with older people in a variety of settings, including hospitals, nursing homes, and the community. I subsequently developed an interest in both decision-making and Gerontological Nursing that I have pursued ever since.

Following my Masters degree I completed an MPhil at the Chinese University of Hong Kong focusing on the experiences and perceptions of clinical decision-making among baccalaureate-prepared Chinese nurses. Although my MPhil study did not focus on nurses' clinical decision-making with older patients, the participants emphasised the complexities of clinical decision-making for older patients during their interviews.

During my time at Hong Kong, Prof. Mike Nolan delivered three research seminars and shared his work on creating partnerships between family and formal carers, developing and applying the Senses Framework and promoting culture change in care environments for older people. I listened to and learned from these presentations, and decided to undertake PhD studies at the University of Sheffield focusing on decision-making with older people and their family carers.

There are also personal reasons why I am particularly interested in exploring decision-making following stroke. My mother suffered a minor stroke a few years ago, and I had the experience of making decisions with my mother as a health professional as well as a daughter. My experiences of making decisions with my mother highlighted the important role that Chinese culture played in health care decision-making. For example, family members are seen as the primary decision-maker for their relatives (Wong and Pang, 2000), children should show filial piety towards parents (Zhu and Cheng, 1997), and the oldest son or daughter has higher status within the family as Chinese culture promotes a hierarchical social structure

in families, in which older siblings are 'superior' to younger ones (Zhang, 2000; Zhu, 2000).

In the early stage of her stroke recovery my mother needed acute treatment and care interventions, which were basically determined by doctors with the informed consent of my older sister. However, when my mother was considered medically stable and fit for discharge, my sister made decisions based on her own knowledge and judgment about my mother's health condition and her readiness for discharge from hospital. She also needed to take into consideration whether my parents' living environment was well prepared, who would provide care, and the availability of family members on the day of discharge. She took the lead role despite the fact that my husband is a neuro-surgeon, and I am an experienced nurse, as both of us were seen as subordinate to my older sister. As a result, we were unable to get fully and actively involved in decision-making for my mother throughout her disease process and stroke journey.

The combination of the above factors provided the major motivation behind this study, in which, as will be clear later, I would like not only to add to understanding about decision-making in stroke within a Chinese context, but to also generate insights that might improve practice if necessary. Having briefly discussed my personal reasons for conducting the study I now outline the structure of the thesis itself.

Outline of the Thesis

This thesis is organised as follows:

Chapter two provides background information and the context for the study of stroke patients' and carers' decision-making in China, and identifies and explains the rationale underpinning the study. Important issues addressed include: the characteristics of stroke and decision-making in the context of stroke care; the role of Chinese culture in health care practice and decision-making; background information about the study setting; the major characteristics of the Chinese health care and social health insurance system and the impact of these on decision-making. Finally, the aims and significance of the study are considered.

Chapter three comprises literature reviews on health care decision-making in general, decision-making with older people and family carers, decision-making

with older patients and family carers in the context of stroke, and the role of culture in health care decision-making. Based on a consideration of the literature, the sensitising concepts and foreshadowed questions that frame the study are identified.

In Chapter four, the methodology underpinning this constructivist grounded theory (GT) study is described including the rationale for selecting qualitative research, considerations informing the use of a constructivist GT approach, important methodological issues, the constructivist GT study process and its application, theoretical sampling decisions, data collection procedures and analysis methods, quality criteria for the study and ethical considerations.

In Chapters five and six the major findings from semi-structured interviews and non-participant observation are presented, describing study settings, socio-demographic characteristics of participants, major categories identified from data analysis, and a mid-range theory of decision-making with stroke patients, family carers and professionals.

In Chapter seven, a reflexive account of methodological issues affecting the quality of the study is presented, followed in Chapter eight by a discussion of the findings relative to the study aims and the existing literature. In the final chapter recommendations for further study are discussed, and the implications for practice and education are considered.

CHAPTER 2: BACKGROUND AND CONTEXT FOR THE STUDY

This chapter provides background information and context for the study of stroke patients' and families' decision-making in China, and considers the rationale underpinning the research in more detail. It begins with a brief introduction to the challenges posed by stroke, illustrating the epidemiology of stroke within China and worldwide and raises issues about decision-making with stroke patients and family carers. The role of Chinese culture in health care practice and decision-making is then briefly considered so as to highlight the need for further research in the Chinese cultural context. Subsequently, background information about the setting, the health care system and social health insurance system in China are provided, including:

- A brief introduction to the city, the hospital and the neurological department where the study was conducted;

- The influence of the Chinese health care system on people's hospital choice and health seeking behaviours, their access to both traditional Chinese medicine (TCM) and western medicine services, national guidelines for stroke care in China, and the important role of the family in stroke care;

- An overview of the social health insurance system in China including: historical development (see Appendix 1); the current scheme and recent reforms; role of private insurance; problems encountered during the implementation of the health insurance system; the challenges facing older people, in particular patients with stroke; the health insurance system in the City of Tianjin and its impact on medical services in the study hospital.

This level of detail is required to help the reader who is not familiar with the complexities of the Chinese system of health and social care to better understand the factors potentially influencing the decision-making process.

The chapter concludes with the aims and significance of the study.

The Challenges of Stroke

Epidemiology of stroke worldwide and in China

Stroke is a major public health concern worldwide due to its significant mortality and long-term morbidity (Kahraman and Jones, 2009). It is the second leading cause of mortality in adults aged 15+ after heart disease. In 2005, there were an estimated 16 million first-ever strokes, and approximately 5.7 million deaths worldwide (Strong et al., 2007). According to Strong et al. (2007) these figures are expected to increase to 18 million first-ever strokes and 6.5 million deaths in 2015, and to 23 million first-ever strokes and 7.8 million deaths by 2030. Meanwhile, there were an estimated 62 million stroke survivors globally in 2005, a figure expected to rise to 67 million in 2015 and 77 million in 2030.

In China, according to the official statistical data from the Ministry of Health (2009), stroke was the third and the second most common cause of death among urban and rural residents respectively in 2008. Its mortality was 120.79 per 100,000 per year in urban areas, and 134.16 per 100,000 in rural regions. It was estimated that about 1.5-2 million people have a stroke each year, and more than 1 million Chinese residents die from stroke (Liu et al., 2007).

In terms of the impact of stroke on the economy, stroke is of increasing concern, being a major burden on the Chinese economy and productivity, due to the high rate of disability and recurrence. Currently the cost of prevention and treatment of stroke is more than 40.0 billion RMB Yuans (equal to £3.6 billion) each year in China (Wang, 2012). Take cerebral infarction as an example, according to the Chinese Statistical Yearbook on Health Care 2010 (Ministry of Health, 2010), the in-patient treatment cost for patients with cerebral infarction in public hospitals in China has increased from 1.17 billion RMB Yuans (equal to £0.11 billion) in 2003 to 8.19 billion RMB Yuans (equal to £0.74 billion) in 2009, at an average annual growth rate of 117 %, in other words, there are 7 times increase in the cost during 6 years.

Stroke is mainly a disease of older people, and its incidence increases with age with the highest rates in people aged 75 and over. The incidence in this age group is 30 times higher than in the group aged 35-44 years (Liu et al., 2007). There is a growing ageing population in China and worldwide. For example, by 2025, 20.0% of Chinese population (0.29 billion) will be 60 years old and over, and by 2050,

those aged 60 and above will account for 33% (0.40 billion) of the total population (Rao et al., 2012). It is anticipated that a rapidly ageing population will lead to a further increase in the number of strokes in the future.

Stroke has multiple impacts on a person's health, and can result in physical, psychological and social problems and functional deficits, exerting a negative influence on overall quality of life, especially for older patients with complex health conditions, and co-morbidities (Sneeuw et al., 2007). From the stroke survivors' perspective, stroke is perceived as comprising multiple 'losses', including reduced physical and functional ability, emotional and social losses, as well as changes in identify (Hilton, 2002; O'Connell et al., 2001; Eaves, 2000; Ellis-Hill et al., 2000). Moreover, the impact of stroke is not confined to the patient but also has major repercussions for the wider family (Brereton and Nolan, 2002).

Decision-making with older stroke patients and family carers

Questions about how health care decisions are made are becoming increasingly important as new technologies are developed and greater attention is placed on patients' and families' participation (McKevitt et al., 2004). Following an acute stroke both older people and their family carers often have to make major life decisions in a relatively short period of time (Brereton and Nolan, 2002).

The literature suggests that stroke patients regard both advice from professionals and their family as important in helping them make decisions (McKevitt et al., 2004; Cox et al., 1998). In a Western context Gibson (2002) found that when making treatment decisions, stroke patients usually see the role of professionals as being to provide options, with the final decision being theirs. It is therefore essential that health professionals provide accurate information about treatment and care options.

The crucial role played by family members has also been acknowledged, with stroke typically being recognised as a 'family illness' (Brummel-Smith, 1994; Evans et al., 1994; Bishop, 1980). However, several studies have reported that carers often make decisions about the future care of the stroke survivor without an adequate understanding of stroke and its consequences (Brereton and Nolan, 2002; Wiles et al., 1998). This situation often leads to carers feeling uncertain and actively searching for the information and skills required so that they feel competent, confident and safe to provide the care needed (Brereton and Nolan, 2002). As a result family carers, in both hospital and community settings, seek to establish

partnerships with health care professionals based on mutual respect and trust between the two parties (Brereton and Nolan, 2003).

Whilst it seems that a number of studies have explored decision-making both about health care in general and stroke in particular (see next chapter for more detail) there is a need for further work about how people with stroke, their families and health care professionals can work together more effectively. This is especially the case in a Chinese context where both cultural factors and the Chinese system of health and social care are likely to exert significant influences.

Role of Chinese Culture in Health Care Practice and Decision-Making

It is recognised that culture has a significant influence on the practice of health care (Leininger and McFarland, 2002). Therefore Chinese culture, which is defined as a set of values, beliefs, attitudes, ways of thinking, and behaviours that underlie social interaction among Chinese people and is what distinguishes them from different nationalities (Fan, 2000), is likely to play an important role in decision-making.

Several aspects of Chinese culture are likely to be influential. For example, it is the moral duty and traditional practice for family members to take care of their sick relatives and make health care decisions on their behalf (Wong and Pang, 2000). Chinese children are expected to show their older parents filial piety which is considered the most important Confucian tradition (Zhu and Cheng, 1997).

The traditional role of family members in Chinese health care context has also been emphasised by nurses. In order to promote their image and status as knowledgeable health care professionals, Chinese nurses regard "treating the patient as their own family member" as their ideal of service (Wong and Pang, 2000, p. 14). In addition, the Chinese tradition of respecting older people also influences nurses' decision-making for older patients. For example, Chinese nurses needed to follow Chinese tradition by showing respect to older patients by obeying them. This might inhibit nurses' decisions for older patients, especially if patients hold a paternalistic attitude towards nurses (Wang, 2009). Such factors further highlight the need to study decision-making in stroke within a Chinese cultural context. This is something that will be considered in greater detail in the next chapter. Another factor likely to play a major role is the way in which health and social care systems operate in China.

Health and Social Care Systems in China

Hospital choice and health seeking behaviours

In the Chinese health service structure, there are two broad types of hospital, general hospitals and specialised hospitals which have specific expertise in managing patients with different health problems, such as neurological diseases, diabetes, dental problems, cancer, mental health conditions and so on (Hougaard et al., 2011). Hospitals are also divided into three different levels according to their scale and scope of services provided:

- Level 1 hospitals have less than 100 beds, operate at township level, serve less than 100,000 people, and mainly provide primary health care services such as disease prevention and rehabilitation;

- Level 2 hospitals have 100-500 beds, operate at county/district level, serve hundreds of thousands people, and mainly provide acute medical care services;

- Level 3 hospitals have more than 500 beds, operate at national/provincial/city level, serve more than 1,000,000 people, and mainly provide acute medical health care services.

Moreover, hospitals can be divided into public or private hospitals (Hougaard et al., 2011; Wu, 1997).

Unlike most Western countries, China does not have general practitioners and a well-functioning medical referral system, therefore people can choose directly between different levels or types of hospitals if they need health care, with the OPD or A & E of the chosen hospital fulfilling the role of a general practitioner. If patients' health problems are beyond the expertise of the chosen hospital, they will be referred to a higher level of hospital (Hougaard et al., 2011).

However, as people generally believe that hospitals at higher administrative levels offer better services (Eggleston et al., 2008), they prefer to go to a higher level or top-ranking hospital for all their health problems, even minor incidents. This situation produces long waiting lists and limited hospital bed availability, heavy workloads for staff members, and ties up health resources at higher level medical

facilities.

Alternatively, patients and their family members may prioritise other factors over hospital scale or quality of service in choosing health facilities, and may choose lower level (e.g. township) hospitals for convenience or proximity to where they live, or because of their preference for a particular local doctor (Brown and Theoharides, 2009).

The potential problems caused by free choice of hospital is that patients may not be able to choose the most appropriate hospital at their first attempt, and may have to change hospitals due to referral or transfer. This potentially creates structural barriers in the health care system inhibiting patients and families from exercising genuine choice. This can lead to help-seeking delays, with negative consequences for a patient's health.

Integration of traditional Chinese medicine and modern western medicine

TCM is one of the world's oldest medical systems and has a history of several thousands of years. It is widely regarded by the Chinese population. The therapeutic approaches of TCM such as acupuncture, moxibustion, tuina bodywork, herbal medicine and qi gong are based on the Chinese philosophy of the correspondence between nature and human beings. It is recognized that TCM has made a great contribution to maintaining and improving the health of Chinese people (Chen and Xu, 2003).

In China, western medicine and TCM have been practised alongside each other since western medicine was first introduced into China in the middle of the 17th century by missionaries (Zhang et al., 2011). The government has been encouraging the integration of TCM and modern Western medicine for more than 60 years since 1949, and such integration is one of the fundamental principles of the Chinese health care system (Chen, 1987). A national health policy of developing and integrating both disciplines has also been stipulated in the 21st article of the Chinese constitution (The Central People's Government of the People's Republic of China, 2005).

Consequently in most western medicine hospitals in China there is a TCM department where specialists provide health care services to patients with different types of conditions. In some hospitals there is even a department of combined

Western-Traditional Chinese medicine, in which health professionals educated in both traditions collaborate with each other and jointly manage and solve patients' health problems. Similarly, in the majority of TCM hospitals where the traditional system of care predominates, there are also western medical departments where health personnel provide western medical interventions (e.g. surgery) for patients (Tian, 2011; Wei and Chen, 2011).

As a result, it is very common for Chinese patients and their families to consult both medical disciplines when seeking health care. They have the autonomy to choose their preferred medical system, and the decision is usually made based on their own knowledge or understanding about the disease, or advice and recommendations from various sources, including doctors (Tian, 2011; Wei and Chen, 2011).

In China, although Modern western medicine is the primary source of prevention and treatment for the management of stroke, most patients with stroke are treated with one or more types of TCM therapies such as acupuncture or Chinese herbal medication in addition to western medicine interventions (Wu et al., 2007; Liu, 2006). For example, acupuncture is considered to have biological effects that can potentially improve recovery from stroke or facilitate the outcome of stroke rehabilitation (Wu et al., 2006). Consequently the role of TCM cannot be ignored.

National guidelines for stroke care in China

In order to help physicians implement evidence-based medical practice and choose the best possible diagnosis and management plan for patients with stroke, Chinese guidelines for the diagnosis and management of acute ischemic stroke were developed. These consider the organisation of services and mainly focus on acute hospital care and interventions (Chinese Medical Association's Neuropathy Branch for Cerebrovascular Disease Study Group, 2010).

The guidelines address major issues such as stroke recognition and pre-hospital care, emergency diagnosis and management, stroke unit care, acute diagnosis and treatment including TCM therapy (e.g. Chinese herb medicine and acupuncture), and management of acute complications.

However, although the guidance is based on the systematic identification and synthesis of the best available scientific evidence, and makes clear

recommendations for health professionals practicing in a Chinese health care context, it includes little information on rehabilitation, focusing primarily on the acute stage of the stroke trajectory.

With respect to the current study there is very little guidance on decision-making with patients or carers, this being limited to the areas of nutritional support, thrombolytic treatment and acupuncture therapy. For example, it is suggested that: percutaneous endoscopic gastrostomy (PEG) tube feeding can be given if patients or their family carers agree; that patients or their family carers should give informed consent before thrombolytic treatment can be implemented; and that decisions about acupuncture therapy should be based on the patient's specific condition and their agreement to such therapy.

Compared with the stroke guidelines developed in western countries, such as the UK, the Chinese guidelines do not pay explicit attention to how principles such as participation, involvement, and partnership working should be applied. These concepts figure prominently in UK guidelines (Royal College of Physicians Intercollegiate Stroke Working Party, 2012a; 2012b), which place considerable emphasis on patient involvement in decision making, participation in health management, and partnership working between patients and health professionals.

In contrast the Chinese guidelines accord family carers an active role in several decision making situations, whereas the UK guidelines strongly advocate the patient's right to be fully informed and to be the primary decision-maker. The input of family carers is at the patient's discretion.

As a result, Chinese health professionals, particularly physicians, have very limited guidance on the involvement of patients in decision-making, and there is no indication on how such involvement might be facilitated. In summary, the Chinese guidelines focus primarily on treatment related decisions in the acute phase, with little emphasis on rehabilitation and no suggestions as to the role of the patient in making any decisions.

Role of family members in acute health care

In contrast to the situation in western countries, and due in part to the limited availability of nurses, family members routinely accompany the sick person into hospital and have a major role in providing care (Lee, 2001). Such family members

are expected to stay with and take care of their relatives on the ward during their hospitalisation, and often take turns staying at the bedside around the clock in order to provide care and offer encouragement and support (Schneider, 1993) as well as undertaking basic bedside care to meet patients' physical needs, and providing psychological and social support to their relatives. This can create problems such as overcrowded ward environments, potential difficulties in maintaining quality of care, and a heavy burden of care for family members (Xu et al., 2005; Lee, 2001).

Following a stroke it is therefore common for family members to accompany their relatives in an acute care setting (Pang et al., 2000). Families are generally the main sources of basic daily care and support throughout the whole patient journey from admission until discharge home and indeed throughout the remaining stroke trajectory. One or more family members are allowed to be present 24 hours a day and are actively involved in the hospital care of patients especially when patients are in a serious condition. Not surprisingly therefore families are often closely involved in decision-making processes.

Supporting stroke patients is stressful despite the fact that family members are willing to take on the filial or spousal responsibility of looking after their sick relatives and meeting their needs (Li, 2005). It is widely recognised that family carers of stroke patients often suffer from increased burden and deterioration in their own physical and psycho-social wellbeing (Xie et al., 2000), such as headache, general malaise and fatigue, depression, anxiety, loss of work hours, and leaving the labour force early because of caring responsibilities (Qiu and Li, 2008; Tong and Qi, 2005; Pang et al., 2000).

Given the major role that they play it is important for Chinese health professionals to give sufficient attention and assistance to family members during hospitalisation, such as giving information related to stroke, providing necessary support, as well as teaching appropriate caring skills, to help them make better informed decisions (Li, 2005).

This reinforces the importance of including family members in the present study if a full understanding of decision-making in stroke is to emerge.

Another facet of the Chinese system that is likely to exert a major influence on decision-making is the current reimbursement policy.

Recent developments in the social health insurance system in China

Since the 1980s, China has placed health insurance reform high on its policy agenda (Naylor, 1999; Phua, 1999), and has undertaken a series of health insurance system reforms to achieve fundamental objectives, such as cost containment, controlling medical cost escalation, relieving the financial burden on enterprises, decreasing the inequality of health care expenses, and increasing the level of risk pooling.

After holding the first National Health Conference to make major health policies for the next decade in December 1996, the Central Party Committee and State Council announced landmark decisions on health care reform and developments in January 1997 (Yang et al., 2010; The Central Party Committee and The State Council, 1997). Major reforms included "establishing effective mechanisms for controlling health care demand and supply, actively seeking appropriate payment methods to control excessive health care costs and gradually expanding coverage to all the urban workers" (Liu, 2002, p. 138).

At the same time, a new Ministry of Labour and Social Security was also established to take charge of the reforms. The State Council also announced a major policy decision to establish a nation-wide social insurance programme for all urban workers in December 1998, to replace the original two tier system (i.e. the Labour Insurance Scheme and Government (employee) Insurance System).

Compared with the old system, the new system aimed to expand coverage to employees in private enterprises in order to provide benefits to all urban workers, and to provide more stable financing with risk pooling at the city level (Liu, 2002). Self-employed and rural industry workers may buy into the programme, but are not required to enroll. However, workers' dependents are not covered.

In July 2000, the State Council held an important meeting in Shanghai to develop major reform policies for basic health insurance system for all urban workers throughout the country, and reform policies for medical care and pharmaceutical sectors. A total of nine policy guidelines and documents were announced, which formed the fundamental reform policy framework to guide the procedures and strategies during the reform process (Yang et al., 2010; The State Council, 2000).

Other major health insurance reforms addressed more fundamental issues aimed at expanding health insurance coverage to benefit both rural populations and urban residents. For instance, in 2003, the State Council announced the decision to establish a New Rural Cooperative Health Care System to re-establish health insurance for the rural population nationwide (Yang et al., 2010; Dumoulin-Smith, 2008), and to change the current situation in which many patients in rural areas had to pay their own medical expenses in full or sometimes even had to borrow money in order to pay the costs (WHO, 2005; Liu, 2004).

In July 2007, the State Council issued another important policy decision, Guiding Opinions of the State Council about the Pilot Urban Resident Basic Medical Insurance, the goal of which was to establish a health care insurance system that covered everyone, especially one group yet to have access to medical insurance, namely non-employed urban residents (The State Council, 2007). This new policy also addressed the future prospects of the urban medical insurance and highlighted attempts to bring rural and urban systems closer together (The State Council, 2007).

In 2007, during the 17th National Congress of the Communist Party of China, Vice-Minister of Health Gao Qiang said at a joint news briefing that 'all people in urban and rural areas will enjoy basic medical care and health services by 2020' (Tian, 2007). This will help to achieve the fundamental goal of a health system defined by WHO in its World Health Report 2000, which is to promote, restore or maintain the health of the population (WHO, 2000).

Whilst these series of reforms addressed the state sponsored system there is also an emerging private sector.

The role of private insurance

In China, private insurance schemes have been established since the 1990s to cover the medical and health needs of the uninsured population (Xu et al., 2007). However, the private insurance sector still plays a very limited part, although currently there are more than 200 life or property insurance companies across the whole country offering health or medical insurance products (Liu, 2002).

Most of these cover particular diseases such as cancer, congestive heart failure, or other critical conditions, rather than benefit people with disability or those who have long-term care needs. However, private insurance can be supplementary to the

country's basic health care insurance system, and is a good scheme for the currently uninsured people, such as self-employed urban workers and rural industrial workers (Chen, 2004).

Moreover, the population covered by the health insurance scheme may also need to purchase supplementary commercial insurance from the private sector, mainly because the current health insurance package sets a ceiling of four times of the average wage, which mainly covers in-patient expenses. Therefore, private insurance can help cover people's health expenditure which exceeds this ceiling. In addition, private insurance can also help cover the cost of health care services excluded from the social health insurance system, such as those which are not on the official list of essential services or medications (Yang et al., 2010; Liu, 2002).

Major challenges

Despite having made many reforms in recent years to enable Chinese people to enjoy affordable and high quality health care, China still faces several major challenges. For example, as a large country, China demonstrates significant socio-economic variation among different geographical regions (Dumoulin-Smith, 2008; Liu, 2002). Therefore, it is very difficult to establish a uniform benefit package which can meet the diverse needs of local citizens.

Another important issue that needs to be addressed is the coverage of catastrophic diseases, such as severe cancer, heart attack, or stroke. Since the current system sets a ceiling at four times the average wage, most catastrophic illnesses are left uncovered, and people may have to purchase private insurance to cover those kinds of diseases. This is especially true for older people (see below), who are more likely to develop chronic diseases and suffer from critical conditions or severe life-threatening episodes.

Other problems encountered during the implementation of the health insurance scheme include inadequate responsibilities of operation and management taken by central government to ensure the stability and equity of the health insurance system, and lack of sound auditing and monitoring procedures leading to problems with supervising its implementation (Yang et al., 2010; Dumoulin-Smith, 2008).

The above challenges prevent China from fully maintaining equity and reducing poverty, and improving population health status (the State Council, 2000). Health

insurance reforms are still incomplete and inadequate, and China needs to make greater efforts to establish a universal health insurance scheme that enables all citizens to afford decent health care (Dumoulin-Smith, 2008). As will be seen in the results later issues of cost play an important role in decision-making in stroke.

Many of the above issues are exacerbated for older people.

The current situation of health insurance for older people

The ageing of populations is a global trend, and China is no exception with the situation being exacerbated as a result of the dramatic fertility decline due to its 'one-child' policy (Yang and Leng, 2010). Chinese population ageing has particular characteristics (Liu and Zheng, 2009). Firstly, it has the largest absolute number of older people in the world. Secondly, given the fact that China is 'getting older before getting richer' its social economy is not yet fully developed and the rapidity of the growth in older people has led to unmet health care needs, decreased health status, and poor recovery (Huang, 2005).

The growing ageing population in China has a potentially serious impact on the health care insurance system. Therefore, under the current social health care insurance scheme, increasing attention has been paid to several issues, such as what older people's health care needs are, and how to effectively provide financial support and insurance benefit to meet their needs and maintain their health (Jia, 2004).

The health insurance system has two main limitations concerning the older population in China. The first one is inadequate coverage, especially for older unemployed urban residents. For example, in 2006, about one-third of the urban older population were not covered by health insurance (Jiang et al., 2010). Many of them have no income at all yet place higher demands for health care services and insurance. Consequently, the current system cannot provide effective protection for their benefits (Liu and Zheng, 2009). Indeed, due to the lack of adequate health insurance coverage, older patients and their family carers have to bear a significant proportion of the cost themselves. This, combined with the increasing health care costs related to examinations and treatments, increases the economic burden of chronic conditions such as stroke in China (Wei et al., 2010).

The other problem with the health insurance system is that it does not take into account the older population's special health care needs. Older people have higher disease incidence, and more dependence on health insurance than other people. However, the health insurance system fails to give preferential consideration to older citizens (Liu and Zheng, 2009).

Therefore, despite the series of recent major reforms to health insurance schemes the system is still not able to fully meet older people's health care needs (Yang and Leng, 2010). This can have serious consequences.

Non-hospitalisation is more common amongst non-insured older people, as even though they are referred to hospital, they often choose to decline admission due to financial difficulties (Jun et al., 2007).

To enhance access to social health care insurance for older people, the government needs to involve major stakeholders, such as health care providers and older people when making major policy decisions (Liu, 2002). Recently China has made moves to expand the health care insurance coverage to both urban and rural populations and this has the potential to reduce the economic impact of illness, such as stroke, on older patients, their carers and society (Wei et al., 2010). Many of the above problems particularly affect older people with stroke.

In common with other forms of cardiovascular disease, stroke can cause considerable economic hardship to patients and families due to loss of income and the cost of health care (Abegunde et al., 2007). For example, medical care in the acute hospital, discharge follow-up, rehabilitation (e.g. acupuncture, functional training), continuing care in the OPD, together with care at home (e.g. by families or domestic helpers) all require financial expenditure. As a result, patients, especially those who do not have the benefit of health insurance coverage, may worry about seeking medical care, leading to further deterioration in their health (Li, 2005). Stroke patients with low incomes and low levels of insurance coverage, especially those rural citizens, often fail to present to the hospital (Heeley et al., 2009).

Having considered the cultural and structural factors that help to provide a context and background for the study attention is now turned to the setting in which the study was undertaken.

Setting: the City of Tianjin

Tianjin is one of four municipalities directly under the administration of the central government and is the third largest city in China. It is the birthplace of China's modern industry, and one of the earliest modern coastal cities to open up to the outside world. The city is located close to the capital Beijing, and has a population of over 15 million people and a total area of 15,000 square kilometres (Tianjin Municipal Tourism Bureau, 2009). Currently there are 1.71 million people aged 60 and above in Tianjin (Tianjin Daily, 2010), making it one of the top five cities with an ageing population in the country. By 2020 and 2030, 2.73 and 3.3 million people will be 60 years old and over respectively (City Express, 2010).

Tianjin is situated in the eastern part of the North China Plain, and is rich in petroleum, natural gas and sea salt along the coastal area. As one of China's biggest industrial centres, Tianjin has built up an extensive industrial economy with machinery, electronics, textiles, chemicals, metallurgy, and foodstuff as its mainstays. It is also a key hub for land, air, and sea communications. Tianjin has a well-developed road transport network as well as a regular national and international air-service. The seaport is the most convenient sea outlet for Beijing, North China and Northwest China. Efforts are being made to develop Tianjin into a financial centre in North China and an international commercial city (Tianjin Municipal Tourism Bureau, 2009).

The hospital

This study was conducted at a teaching hospital in Tianjin China. The hospital is a general and teaching hospital affiliated with a medical university, with 2150 health professionals, 1200 beds and 36 clinical departments including medicine (e.g. neurology, cardiology, respiratory, hematology, endocrinology, nephrology, and gastroenterology), surgery (e.g. general surgery, neurosurgery, orthopedics, burns, urology, thoracic surgery), gynaecology and obstetrics, paediatrics and TCM.

The hospital was established in 1949, and occupies a total area of 68,000 square metres. It is the largest and most competitive hospital under the administration of the Municipal Health Bureau. Three quality control centres at municipal level for medical imaging, nursing care, and case management and six research institutes are also based at this hospital. It has been awarded 'the best rated hospital in quality services' at a national level, and is held in high regard by citizens.

The neurological department in which the data were collected was established in the early 1970s, and is one of the most famous neurological departments in the city. A total of nearly 70 health personnel provide investigations, treatment, and nursing care services for patients with neurological diseases, such as cerebral vascular disease (e.g. stroke), infectious diseases of the nervous system, pathological changes of peripheral nerves, epilepsy, dementia, headache, vertigo, and hereditary disease of the nervous system, as well as neurological problems caused by illnesses to other body systems. Two physiotherapists and one acupuncturist from their own departments (i.e. physiotherapy department and TCM department respectively) work closely with patients with neurological disease.

As is typical in all other teaching hospitals, health professionals play an important part in providing clinical education and training to the doctors and nurses of tomorrow, and also promote continued learning and professional development among its own staff and people from other hospitals or health institutions in different cities across the country. There is a strong commitment to research, and health professionals carry out a series of research projects and have developed strong cooperative relationship with international colleagues from other different countries.

The director of the neurological department is responsible for the overall management of the medical staff who are divided into four different teams. Patients are assigned to each team by the chief resident physician based on considerations such as which physician is on duty on a particular day, the workload of different teams, and patients' or carers' special preference or needs. Each medical team is usually in charge of around 20 patients who will be the responsibility of the team for their full hospital stay.

Nursing services are provided on a 24-hour basis, with three 8-hour shifts. The head nurse is expected to lead nursing staff while managing the work systems and processes on their wards to ensure that the needs of patients are met and that staff receive the necessary support. The office nurse is a senior level nurse, and focuses mostly on processing medical orders and maintaining patients' records, and performing administrative duties on patient flow such as admission, discharge and transfer across different departments or units or different hospitals. The office nurse also functions as a deputy head nurse when the head nurse is on leave.

Staff nurses are assigned to a particular ward area or unit on a particular day or shift by the head nurse based on staffing levels, skill of individuals, and patient needs, and work closely with patients and carers when undertaking nursing care activities. Nurses carry out medical orders, and complete medical treatments and routine tasks, and work either according to regular office hours, i.e. from 7: 30 am to 5: 30 pm, or shift hours.

In addition to providing routine medical and nursing care interventions, staff members also organise a wide range of activities on a regular basis such as shift change meetings, medical or nursing ward rounds, discharge discussions, case conferences, staff meetings, staff training sessions (e.g. workshop or seminar), and health education sessions particularly for patients and carers.

There are four wards located on two floors, and nearly 100 beds, with single, double or three beds in each room. Patients either have a single room or share the room together with one or two other patients of the same gender. There are bathrooms and toilets in each patient room. Other important facilities include the doctor's office, nursing station, examination room, treatment room, meeting room, and staff lounge.

Patients' family members, friends or colleagues can visit or stay with them during their hospital stay in order to provide psychological support, monitor and report changes in patients' condition and carry out some bedside care activities. This practice is commonly found in other hospitals within the city.

Health insurance system in the city of Tianjin

Since Tianjin is the third largest city in China, and as most stroke patients are retired employees of government organisations, institutions, or enterprises in Tianjin Municipality, the health insurance system for urban employees is taken as an example to illustrate the implementation of health insurance system in this city.

In November 2001, the Tianjin Municipal Government issued the Regulation of Basic Health Insurance for Urban Employees in the City of Tianjin (Tianjin Municipal Government, 2001), which was based on policy guidelines announced by the State Council in 2000, together with a consideration of the current specific situation in Tianjin. The main purpose of the regulation is to benefit all the current and retired urban employees and to ensure their basic medical care. The target

population includes the working or retired employees of government, institutions, and enterprises within the Tianjin Municipal Administrative Region. The Municipal Bureau of Labour and Social Security are responsible for the implementation of the health insurance system, in cooperation with other bureaus involving the areas of finance, health, commodity prices, auditing, and drug administration.

The health insurance is funded by the contributions coming from both employees (2% of the employee's wage) and employers (9% of their wage), which form the main components of the fund. It finances health care services via two means: individual medical savings accounts and social risk pooling at the city level. Male or female retired employees are exempt from the premium contributions if they have already made aggregate contributions for 25 or 20 years respectively. The funding in the individual medical savings accounts consists mainly of contributions from employees and a certain percentage of the contributions from employers (Tianjin Municipal Government, 2001).

The funds from both the individual medical savings account and social risk pooling is used to pay or refund the medical care services which are regulated as eligible based on the Essential Services Lists and the Essential Drugs Lists, which were developed by the central government in June 2000, and specify which services and drugs are covered or not covered by the health insurance system (Zhang and Shen, 2004). Local governments are authorised to make minor alterations to the lists, such as expanding or reducing the items by up to 5% (Liu, 2002). According to the local regulations (Tianjin Municipal Government, 2001), individual medical savings accounts are mainly used to cover employees' costs at the out-patient department and accident and emergency department of the medical insurance designated medical institutions. It can also pay for the cost of drugs at the medical insurance designated retail pharmacies or drug stores. The social risk pooling is mainly used to cover inpatient related expenditures in the medical insurance designated medical institutions of up to 85% and 90% of the inpatient costs for current employees or retired employees respectively.

However, the basic health insurance will not pay for costs incurred when employees use non-medical insurance designated hospitals, drug stores or other kinds of health care facilities. This gives the employees with eligible health insurance a certain amount of freedom when they make choices about which medical insurance designated hospital to seek medical help. In addition, a cost ceiling at four times the average wage for using the social risk pooling is also set up according to national

policy. All medical costs beyond the ceiling rate are borne by the employees themselves (Tianjin Municipal Government, 2001).

The Municipal Bureau of Labour and Social Security has the autonomy to designate the institutions (i.e. hospitals, drug stores) as being eligible or non-eligible to provide services covered by health care insurance schemes. It considers the health facilities' qualifications and then issues them with certification. When current or retired employees go to the designated health care institutions to seek medical help, they need to bring insurance certificates with them (Tianjin Municipal Government, 2001).

Currently in Tianjin, all the public hospitals and some of the private hospitals are medical insurance designated institutions. Patients/carers can make their own decisions about which hospital to attend and are given the autonomy to choose health care facilities (e.g. types of ward). All the designated health care institutions must provide health care services strictly under the regulation of basic health care insurance, otherwise, costs will not be reimbursed by the health care insurance system. These measures demonstrate their important role as an effective cost containment mechanism (Tianjin Municipal Government, 2001).

Based on regulations about health insurance coverage for services and medications issued by the Municipal Bureau of Labour and Social Security, different types of medical care, nursing care, and rehabilitation services are not reimbursed by basic health insurance for urban employees (Tianjin Municipal Government, 2001). On the wards for stroke patients in the neurological department these items involve certain examinations, treatments and medications, nursing care procedures or services, and rehabilitation interventions. However, generally speaking, the number of examinations, treatments or other types of services which are not covered by health insurance account for a small proportion of the total number of health care services available for patients/carers.

For example, stroke patients need to pay the costs of Colour Doppler Ultrasound for blood vessels of four extremities and Full Digital Colour Doppler Ultrasound Diagnostic System for cardiac disease. For patients receiving Carotid Doppler Ultrasound Scan, their health insurance only covers the expenses of scanning two blood vessels. As regards Magnetic Resonance Angiography, the health insurance will covers the costs only when patients receive abnormal results, otherwise, patients with normal results need to pay the costs themselves.

Stroke patients can have most of their treatments and medications covered by their health insurance, which includes interventions to lower intracranial pressure and control blood pressure and a variety of medications, such as cerebral metabolic activation agents, thrombolytic agents, anticoagulants, cerebral vasodilator, calcium antagonists, sedative drugs, analgesic, antipyretic medication, lipid-lowering medication, and traditional Chinese medication (e.g. Chinese herb products). Acupuncture therapy is also covered.

However, some of the medications which are listed in the third category of the Essential Drugs Lists issued by government, such as Edaravone Injection (cerebral protective agent), Cerebroprotein Hydrolysate Injection (cerebral metabolic activation agents), and Monosialotetrahexosylganglioside Sodium Injection (cerebral nerves protective and repairing agent), are not covered by the patients' health insurance.

In terms of nursing care services, stroke patients need to pay the full costs for respiratory monitoring, blood sugar testing, oxygen therapy, and BD PosiFlow IV Access System and they pay extra costs for additional vein indwelling needles if they use more than two of them. They also pay about 70% of their hospital bed fees themselves. Patients also need to meet the costs of certain types of rehabilitation therapy, such as eating and swallowing training, and electromyographic biofeedback therapy.

The hospital charges patients the same amount of money for each kind of health care service they receive, whether or not they have health insurance coverage. In other words, the hospital has a uniform charge rate which means that uninsured stroke patients and their families often find it very difficult to afford their health care expenditures.

In terms of length of hospital stay (LOS), although the current health insurance system sets a ceiling at four times the average wage to cover expenditures during hospitalisation, it does not impose a limitation on the LOS. LOS is determined based on a patient's specific condition and is influenced by health professionals' appropriate and effective examinations and treatments.

This chapter aimed to 'set the scene' for the remainder of the thesis by considering a number of factors that are highly likely to exert an influence on decision-making

in stroke in an acute care context in China. The importance of stroke as a major health issue has been highlighted, as has the limited prior work in a Chinese context. The role of culture in decision-making and a detailed account of the health care system in China and its re-imbursement strategy was been considered so as to highlight issues likely to be of significance.

The present study sought to explore the nature of the decision-making process between people with stroke, their family carers and professionals in an acute care context in China. Using constructivist GT methodology (see Chapter four for rationale and description of methodology), the study seeks to better understand the experiences of decision-making from multiple perspectives.

It is hoped that the study will have important implications for health and social care practice, and that the findings will potentially help older patients with stroke and families to make effective decisions in partnership with health care professionals, in order to receive high quality health and social care which best meets their needs and improves their quality of life.

The next chapter describes the literature review process that was undertaken to identify the sensitizing concepts and foreshadowed questions that initially guided the study.

CHAPTER 3: LITERATURE REVIEW INFORMING THE STUDY

Introduction

This chapter presents the results of a review of the literature centred on issues related to decision-making between patients, their families and professionals in health care practice. The reviews focus primarily on older patients', family carers' and health professionals' experiences of making decisions in the context of stroke but also provide a wider overview of other relevant issues, particularly the influence of culture on such decisions.

The chapter begins with a brief consideration of the role of a literature review in GT (see next chapter for rationale for selection of GT). This is followed by an explanation of the literature search strategies used and how relevant sources were selected. Two reviews are then presented. The first brings together the main themes emerging from a consideration of a number of areas relating to decision-making (health care decision-making in general, decision-making with older patients and family carers, and decision-making with older patients and family carers in the context of stroke). A second review considers the potential influence of culture on health care decisions.

After presenting an overview of the major findings from the literature and offering some preliminary interpretations and discussion of key themes, the sensitizing concepts and foreshadowed questions that initially informed this constructivist GT study are identified.

Role of the Literature Review in GT

The present study uses a constructivist GT methodology, the essential purpose of which is to produce a rich understanding of the social world and build explanatory theories that guide knowledge development and discipline advancement, whilst also having the potential to lead to changes in practice (Charmaz, 2006). An important principle of GT is to make a conscious effort to acknowledge preconceived bias, preconceptions and prejudices about the subject under study, and to avoid imposing predetermined and existing theories on the data and its analysis, so as to allow the data to lead the identification of concepts and their relationships resulting in the development of theory that is 'grounded' in the data (Charmaz, 2006). However, despite this guiding principle the role and timing of the literature review in GT

studies is contentious and therefore merits attention.

There has been a long-standing debate about the stage at which existing literature or knowledge should be consulted in GT studies. The classic grounded theorists, Glaser and Strauss (1967) advocated reviewing the existing literature only after completing independent analysis of the data in order to keep researchers away from any prior knowledge and understanding. However, other researchers have questioned Glaser and Strauss's stance and advise carrying out a literature review of existing work prior to the study commencing (Charmaz, 2006; Morse, 1998a). Such a review not only allows the investigator to appreciate the extent of earlier related work, so as to avoid "reinventing the wheel" (Morse, 1994, p. 26) but also provides a theoretical context and rationale for the study, offers ideas for guiding sampling, facilitates generating interview questions and enhances theoretical sensitivity to important concepts or ideas that may emerge from the data (Strauss and Corbin, 1990). Morse (1994) argues that the identification of existing concepts allows the researcher to "recognise leads" without being led by them (p. 27). Others advocate that the literature review in a GT study should be ongoing throughout the research process – namely before, during as well as after data collection (Smith and Biley, 1997).

In the current study I undertook an initial literature review in order to:

- Identify gaps in the literature and justify the need to conduct the study;
- Allow me to build up a broad understanding of the literature in the area of patients' and carers' decision-making within of the context of my study;
- Identify and generate sensitising concepts and foreshadowed questions to inform and guide early data collection and to provide initial direction for the study.

On a more pragmatic level as Ethics Committees require both a justification for the study and an outline interview guide some engagement with the literature is essential.

In this review only the literature that was available at the time the study commenced is considered. Literature that emerged as the study was on-going was obtained but not considered until the study was completed. This literature is considered in the discussion chapter. The initial review of the literature explored a number of broad areas with a progressive focus, including: health care decision-

making in general; decision-making with older patients and family carers; decision-making with older patients and family carers in the context of stroke; and role of culture in health care decision-making. The initial intention was to provide 4 separate reviews addressing each of these areas. However, as analysis of the literature was undertaken the same main themes emerged from the sources on decision-making and therefore two reviews are presented below, one on decision-making and one on culture. I now describe the methods adopted in the review.

Methods (Literature Search Strategy)

The literature searches were conducted using online electronic databases for English and Chinese-language articles published from 1980 to 2010 in order to consider both the latest research and to gain a wider and in-depth understanding of the relevant areas. The databases included ASSIA via CSA, British Nursing Index, CINAHL, EBM Reviews, EMBASE, MEDLINE, PsycINFO, Social Sciences Abstracts, Social Sciences Citation Index, and CNKI for Chinese literature. These databases covered a variety of disciplines including medicine, nursing, psychology, and social sciences. In addition, web-based online sources such as AGEInfo, Cochrane Library, Google Scholar, and Web of Knowledge were also searched using the same search strategies.

The search for unpublished references and papers (e.g. dissertations and conference proceedings) used the following sources: Dissertation Abstracts International, Google Scholar, Index to Theses, Directory of Open Access Journals, and government health department websites. Hand searching of journals in health and social care was also undertaken. Additionally, the items cited in the reference list of the published articles which appeared to be particularly relevant to the present study were also retrieved from the electronic databases and by hand searching in the university libraries.

The key words used for searching were as follows: decision-making (choice behaviour, consensus, negotiating), older people, older patient, patient, family carer (family, caregiver), professional, acute care, health care, social care, health, stroke (brain ischemia, intracranial embolism and thrombosis, intracranial haemorrhages, brain infarction), China, Chinese, culture, and participation (patient participation).

This review considered references which explored the topic of decision-making with patients and their families in health care practice, in particular, in the context

of managing and caring for older people with stroke. The areas of interest included experiences of decision-making throughout the entire patient journey.

Inclusion criteria of the articles were that they clearly described the objectives and methodologies, comprehensively reported and clearly discussed the findings and made conclusions and recommendations corresponding to their specific aims. References which were felt to be particularly relevant to the present study and met the above inclusion criteria were identified and selected. The references which did not meet the inclusion criteria were excluded (an example of a search undertaken can be found in Appendix 2).

The initial reviews of the literature on decision-making identified an extensive number of references, in excess of 8000. After a consideration of the titles the vast majority of these articles were not deemed relevant and as a result the number was reduced to 195. The abstracts of these papers were considered and, subsequently, for those papers that were deemed to be relevant, the full text was obtained and studied in more detail. This led to the inclusion of 65 items within the final review that covered three broad areas concerning decision-making (health care decision-making in general (20 items); decision-making with older patients and family carers (15 items); and decision-making with older patients and family carers in the context of stroke (30 items). As the primary purpose of the literature in constructivist grounded theory is to identify sensitizing concepts and foreshadowed questions that provide initial guidance for the study these three reviews are integrated, with the primary emphasis being given to the literature on decision-making in the context of stroke.

A separate review was undertaken exploring the role of culture in decision-making. This initially identified 2220 references of which 2150 were excluded from a consideration of the titles. Of the remaining 70 references, 14 were eventually included following a consideration of abstracts/full text.

Of the 65 references on decision-making, the vast majority came from Western countries (57/65), mainly North America (n=18), the UK (n=17), and Scandinavia (n=16). Only eight came from Asian/Eastern countries (China n=3, Taiwan n=2, Japan n=1, Hong Kong n=1 and Korea n=1). This reinforced the paucity of existing work exploring decision-making in Eastern cultures and highlighted the need for the study. Not surprisingly the literature on the influence of culture had a greater consideration of Eastern countries with nine of the 14 references obtained

considering an Eastern perspective.

Having obtained the references analysis took two main forms. The first was to provide an overview of the type of studies and their main characteristics. For this purpose the following details were recorded: aims; sampling; design; data collection/analysis; rigour; results and limitations. As the primary purpose of this review is to identify the sensitizing concepts and foreshadowed questions that emerged from the more conceptual analysis (see below) details of the above information can be found in Appendices 3 to 7 for interested readers. From a methodological point of view the majority of the studies on decision-making had adopted a qualitative approach (40/65), 23 had used a primarily quantitative approach and two had used mixed methods. Quantitative approaches were more common in the studies on culture (9/14).

The approach advocated by Nolan et al. (1996) and further developed by Repper et al. (2008) was used to analyse the references that were included in the final review. The same strategy was used for the literature on decision-making and culture. This involves a three stage process of review, analysis and synthesis that has been described in the following way:

> *"In essence a constant comparison approach was applied in which each piece of literature was seen as the equivalent of an 'interview', and a process of analysis and synthesis applied both within and between articles. Consequently, a first reading of each reference was undertaken and detailed notes made, highlighting the main themes or arguments presented. In this way several hundred sides of 'first order' analysis were compiled, identifying initial codes and themes. Subsequently, these codes and themes were re-read and second order analysis undertaken to further refine these, and to identify their differing dimensions...following this a third level of synthesis was completed in order to identify common or unique aspects and to elaborate upon the themes identified in the level two analysis"*
> (Repper et al., 2008, p. 24)

This approach was seen to be particularly appropriate as it was not only based on the principles of data analysis that I would be using in the study but it also allowed me to make comparisons across the three areas of decision-making that I was exploring (health care decision-making in general, health care decision-making in

older people and their carers and health care decision-making in the context of stroke). As noted above it had initially been my intention to conduct and report three separate reviews. However, following the first two levels of analysis it was clear that there was a considerable degree of conceptual overlap between the themes emerging across the three reviews and therefore the synthesis at level three considered all the prior analysis together in producing the overview presented below.

Before presenting the results of the reviews on decision-making and culture it is important to have an understanding of the overall approach to decision-making adopted in this particular study.

Generally speaking, decision-making refers to 'making mental choices between alternatives' (Matteson and Hawkins, 1990) and decision-making with patients and their families is seen as an essential component of health and social care practice (Nordgren and Fridlund, 2001). Given the fact that studies on the health and social care of older patients increasingly focus on "triadic" rather than "dyadic" relationships (Nolan et al., 2004) and since older patients often go to seek medical help with their family members (Haug, 1994, p. 2), it is important to recognise the role played by not only professionals but family members in decision-making by older people.

With the above considerations in mind, and also based on the main purposes of the study, I decided to initially consider decisions made throughout the entire patient journey, but with a particular emphasis on decisions made in an acute care context in order to begin to understand the interactions and relationships between older people, carers and professionals during that process.

This study focused on stroke in an acute care setting for two reasons.

Firstly, as already noted, stroke is a major cause of death and disability in many countries (Kahraman and Jones, 2009), and is the second leading cause of death, and the leading cause of disability in China (Ministry of Health, 2009). An essential component of a comprehensive stroke service is good quality acute care as the correct treatment plays a key role in preventing further damage to the brain, minimising subsequent impaired mental and bodily functions, improving health outcomes, reducing patients' risk of complication, death, disability and dependency, recurrence and costs (NICE, 2008). Therefore decision-making among stroke

patients, family carers, and professionals during acute care phase is vital in ensuring patients' rapid recovery, positive prognosis and improved quality of life. Yet very little is known about this in a Chinese context. This was the primary reason for focusing on acute care.

Secondly, my interest in decision-making in acute care had been stimulated during my MPhil study (see earlier). However this had only involved nurses and I wanted to expand my focus to include not only other professions but also patients and their family carers.

Having set the scene I begin with the results of the review on decision-making.

Key Themes Emerging from the Review on Decision-Making

Following the detailed analysis and synthesis described above a number of key themes were identified from the literature on decision-making:

- Processes of making decisions, including a temporal dimension
- Patients' and carers' preferences for participation in decision-making
- Factors influencing patients'/carers' participation
- Strategies that facilitate or inhibit patient and carer participation
- The role of trust in decision-making

The processes of making decisions

Generally speaking the literature depicts decision-making as a dynamic process during which patients/carers and professionals, primarily doctors, interact with each other. During this process the degree of control varies with some decisions being led primarily by doctors, some by patients, some by carers, and others in partnership (Lown et al., 2009). These authors suggest that dependent upon the associated degree of risk or uncertainty that one or other party either assumes, defers or shares control in decision-making. This was strongly influenced by the relative beliefs of patients and doctors as to the appropriateness of patients exercising a degree of control (Lown et al., 2009).

Other studies suggest that in the case of shared decision-making participants believed that decisions were usually made through a series of (multiple) communications, conversations, and discussions with decision-making being seen

as an ongoing process involving multiple stages rather than a single event. The conversations occurring between patients and professionals were usually about the pros and cons of different options, or the potential to change a particular choice, such as making decisions on medication (Fraenkel and McGraw, 2007a; Elwyn et al., 1999).

The above findings suggest that decision-making can be considered as a complex and dynamic social process in which patients and professionals actively interact with each other. An essential theme throughout this process is the shifting of control and the level of involvement of patients, which is shaped by patients' or doctors' preferences for involving patients. The degree of participation varies from person to person depending on their preference or capacity at different times.

For example Elwyn et al. (1999) reported that doctors considered it essential to ensure that patients were well enough and felt ready to participate before this was encouraged. Taking a different perspective Kelly-Powell (1997) argued that patients' decisions to accept treatment were heavily influenced by their long-established beliefs and views about themselves as individuals. This suggests that a wide range of personal factors (for patients, carers and doctors) are likely to exert a considerable influence and these are considered in greater detail later. Attention is now turned to the literature on the process of decision-making in stroke.

The literature suggests that stroke patients and their families need to make different types of decisions concerning a wide range of issues in health care encounters as well as in their daily life at different stages throughout the entire patient journey. These decisions typically include, help-seeking, medical treatment, nursing care, discharge plans (or plan of care and discharge destination), family care, rehabilitation and end-of-life care.

Such decisions are variously made at the time of stroke/prior to admission, during hospitalisation, at discharge, after discharge home and at the terminal stage of a patient's life. Physical discomforts, problems, prolonged hospitalisation and disability that follow a stroke and the long-term nature of the progression of stroke and its recovery and rehabilitation often lead to ongoing decision-making and interactions between patients, families and professionals. The main focus here, consistent with the aims of the study, will be on early decision-making in the context of acute care. In order to understand these processes a number of models have been suggested.

For example, Moloczij et al. (2008) reported that stroke survivors sequentially go through the processes of recognition, interpretation and negotiation in order to decide whether and when to seek medical help at the onset of stroke.

At the recognising stage, stroke patients or others in their proximity, notice that something is 'wrong' and they need to 'interpret' these signs correctly in order to make sense of what is happening, why and to decide whether medical attention is required. This often requires a process of negotiation with themselves or others to decide if and when to seek help. Depending on the outcome of these processes people decided to either take help seeking action or no action (Moloczij et al., 2008).

Others have suggested that patients demonstrate different levels of participation in decision-making at different stages of their journey. For example, Olofsson et al. (2005) suggested that the majority of patients actively made decisions to seek care at the onset of stroke. However during hospitalisation, it was primarily professionals who make the decisions, with patients being largely passive. Conversely, upon returning home, and in order to regain control of their lives, patients try to actively make decisions with family support.

Proot et al. (2007) carried out a GT study to explore the degree of stroke patients' autonomy from admission to discharge and their findings suggested that in the best cases professionals adopted a phased approach providing full support to the stroke patient on admission, moderate support and supervision during rehabilitation and reduced supervision at discharge. Here the degree of autonomy alters as the patient's condition allows. As a result, stroke patients experienced increased autonomy and more active participation over time (Proot et al., 2007). Other studies in stroke have focused more of the participation of family carers.

For instance, Brereton and Nolan (2002; 2003) found that carers were often required to make decisions about future care of stroke patients without adequate understanding about stroke. This gave them a sense of uncertainty and a lack of confidence in their ability to provide the necessary care. Therefore they engaged in a series of 'seeking' activities, such as: searching for and collecting information or knowledge from a variety of sources; trying to learn caring skills; and seeking partnership, help and support from both families and professionals in order to make themselves feel competent, confident and safe to provide the best possible care for

their relative.

Similar 'seeking' behaviours were also identified by other researchers, although they were not named as such. So Rogers and Addington-Hall (2005) reported that families would search for advice or support from professionals when making end-of-life decisions (e.g. on artificial hydration and nutrition, treatment of infections, or rehabilitation) for older patients with stroke. Studies suggest that the majority of patients and carers have a strong desire to receive detailed and precise information about stroke and treatment in order for them to make decisions (Slot and Berge, 2009; Wellwood et al., 1994).

Hedberg et al. (2008) identified three processes, namely advising, summarising, and intervening, via which stroke survivors, their relatives, and health and social care professionals communicate with each other when making decisions during care planning meetings for patients post-discharge. Advising was mainly used by patients, relatives, and nurses to voice their wishes, summarising was mainly used by social workers to give suggestions during decision-making and intervening was mainly used by nurses when making treatment and rehabilitation decisions.

So far the wider literature on decision-making in health care in general and stroke care in particular suggests that it is a complex process that varies over time, with greater or lesser degrees of participation and involvement by professionals, patients and carers. However the literature also suggests that such involvement is itself influenced by a diverse array of factors. A number of these are considered below, beginning with the extent to which patients and carers actually wish to be involved.

Patient and carer preferences for participation in decision-making

Several studies from the general literature report differing results with regard to preferences for involvement in decision-making. Some found that the majority of patients (Florin et al., 2006; Arora and McHorney, 2000; Levinson et al., 2005) preferred to take a passive role and leave decisions primarily to physicians or nurses. However, other researchers reported that most patients preferred shared decision-making (Zhang et al., 2008; Rosén et al., 2001). It is interesting to note that apart from a few participants in the study by Deber et al. (2007), patients do not seem to want to make autonomous decisions.

Findings also suggest that older people and their family carers sometimes hold different preferences concerning their role in making decisions. Some older patients either did not want to participate in decision-making (Belcher et al., 2006) or believed that they should follow the doctor's 'orders' (Rotar-Pavlič et al., 2008), confirming the passive role suggested by Hasselkus (1992), as opposed to the active role she found that carers wanted to play. Other authors have also described carers as playing a more active role than patients (Marques et al., 2006; Christensen et al., 1989).

Differences have also been identified between patients' preferred role in decision-making, their actual role in decision-making, and nurses' perceptions of patients' preferences (Florin et al., 2006). For example, more nurses than patients perceived that patients preferred a more active role in decision-making about their general nursing, physical and psychological/spiritual needs. However, patients wanted a more active role in decision-making on communication, breathing and pain compared both to nurses' perceptions and the actual role played by patients (Florin et al., 2006).

These findings suggest that professionals and patients may hold differing views as to patients' expectations about participation in decision-making and that expectations vary depending on the type of decisions that were being made. They also indicate that nurses are relatively poor judges about patients' actual preferences and either under or over-estimate these (Florin et al., 2006). However, once again there was little indication that patients wished for a fully autonomous role.

The literature on older people and decision-making also suggested that professionals hold different perspectives about patients or carers participation. Rotar-Pavlič et al. (2008) analysed doctors' perceptions of patient involvement in health care decision-making and found that some doctors would like to involve patients in decision-making, give them advice and allow them to make decisions. Conversely others believed that patients should follow their advice. Whereas in Jewell's (1996) study, nurses believed that it was necessary and important to encourage patients' participation in decision- making and self-care. Similar differences were found in the literature relating to stroke.

It seems that stroke patients and their carers can also hold different perceptions or preferences regarding their participation in decision-making. For example, Hjelmblink (2008) found that some stroke survivors demonstrated a strong need for

autonomy and regarded it as extremely important. Such patients did not want to involve families in decision-making and expected families to agree with or support the decisions they made. Similar findings were reported in other studies, in which stroke patients wanted their autonomy to be respected (Mangset et al., 2008) and wanted to be more involved in decision-making (Payne et al., 2009; Slot and Berge, 2009; Health Care Commission, 2005; 2006). Family members have also reported wishing to participate in making different types of decisions for their relatives including medical, care related decisions and financial decisions (Marques et al., 2006; Christensen and Anderson, 1989).

On the other hand some patients and carers desire lower levels of participation in decision-making. For example, some stroke patients increasingly rely on families, in particular their adult children, to make decisions due to their frailty and physical/cognitive deficits after stroke (Huby et al., 2007). Other patients felt frustrated when they are expected to make decisions, preferring professionals to make decisions for them (Mangset et al., 2008; Huby et al., 2007; Olofsson et al. 2005). Wellwood et al. (1994) found that sometimes family carers also preferred professionals to make decisions.

Such diversity can be explained in part by a range of patient, carer or professionally related factors. The major ones identified in the literature are considered briefly below.

Factors influencing patient/carer participation

Patient-related factors
Patient-related factors were numerous and included:

- Age
The general literature indicated that younger patients were more likely to want a relatively independent role (O'Connor et al., 2003), and desired more active participation and greater collaboration with doctors in decision- making (Chang et al., 2008; Menne and Whitlach, 2007; Florin et al., 2006; Levinson et al., 2005; Henderson and Shum, 2003; Rosén et al., 2001; Arora and McHorney, 2000). In contrast, older patients (typically over the age of 50) were more likely to prefer a passive role and wanted greater input from doctors (Deber et al., 2007; Levinson et al., 2005; Henderson and Shum, 2003). For example, Levinson et al. (2005) found that the preferences for an active role increased with age up to 45 years, but

decreased thereafter.

In the case of stroke a patient's age was found to influence both their degree of desired participation, and the extent to which they sought timely medical help. According to Almborg et al. (2008), younger stroke patients wished for a far greater degree of participation in decision-making about care, rehabilitation, and discharge planning. Chang et al. (2004) reported that older patients significantly delayed their help seeking decisions, arguing that this was due to either earlier negative experiences of hospital treatment or their inability to identify stroke symptoms.

- Gender

The role of gender is equivocal. Female patients were reported to prefer more active participation in decision- making than male patients in some studies (Levinson et al., 2005; Arora and McHorney, 2000), Florin et al. (2006) reported no gender differences, whereas Chang et al. (2008) reported men as wanting a more active role.

Somewhat differing findings emerge in relation to stroke. Andersson and Hansebo (2009) reported that female stroke patients were more willing to have health professionals make care decisions for them, believing that their own knowledge about stroke treatment and rehabilitation was inadequate. Conversely, male stroke patients demonstrated different attitudes, and were more likely to ask questions about their care and rehabilitation, to discuss or question health professionals' decisions, to make suggestions, or to negotiate with professionals. However, in Kapral et al.'s (2006) study, whilst female patients were found to have ambivalent feelings, in that they were less confident than men in their ability to make decisions, they still preferred shared or independent decision-making rather than having decisions made by doctors.

- Educational level

Perhaps not surprisingly patients with higher education levels have been found to prefer more active participation and to hold more positive attitudes towards patients participation in decision-making (Deber et al., 2007; Levinson et al., 2005; Rosén et al., 2001; Arora and McHorney, 2000). They also wanted to share responsibility with their doctors (Smith et al., 2009) and were more likely to question their doctor's judgement and to negotiate with doctors when they disagreed (Smith et al., 2009) than were patients with less formal education.

In contrast patients with lower education levels were more likely to involve doctors in their decision-making process (O'Connor et al., 2003), but would still prefer to make the final decision (Smith et al., 2009). However, if disagreements arose such individuals tended to avoid conflict and to concur with a doctor's recommendations without challenging them (Smith et al., 2009).

Based on the findings from the study undertaken by Almborg et al. (2008), stroke patients with higher than elementary school education were significantly more likely to want to be involved in decision-making about their care, rehabilitation and discharge planning. A closely related factor is the extent to which patients are well informed about their condition.

- Well informed and supported patients

Once again, not surprisingly, patients who had appropriate, relevant, credible and sufficient information are more likely to participate in decision-making (Fraenkel and McGraw, 2007b; Larsson et al., 2007; Biley 1992), as this helps to: dispel their fears; encourage them to raise questions, to consider their choices, and to make a "rational" decision (Smith et al., 2009, p. 1811). Having adequate information about alternative outcomes and possibilities was also identified as essential for satisfactory decision-making (O'Connor et al., 2003). The extent to which patients were well informed is often linked to their relationship with professionals, especially doctors.

When doctors fail to provide adequate and reliable information or were seen to present biased information then patients were reported to encounter difficulties in making decisions (Zhang et al., 2008; 2010), to have more decisional conflict (O'Connor et al., 2003), and to play a more passive role in making decisions (Elwyn et al., 1999). This was compounded when doctors spent little time with patients (Zhang et al., 2008; 2010; Fraenkel and McGraw, 2007b; Elwyn et al., 1999), had poor interpersonal skills (Smith et al., 2009; Elwyn et al., 1999), failed to involve patients in decision-making (Smith et al., 2009; Elwyn et al., 1999), and did not ask patients about their preferred decision-making role (Zhang et al., 2008; Elwyn et al., 1999). The importance of adequate information and support, from both professionals and family carers, also figured prominently in the stroke literature.

Information from professionals has been identified as an important factor influencing stroke patients' and carers' decision-making processes. For example,

professionals' providing useful information through active communication can help patients to more actively participate in making decisions (Health Care Commission, 2006; Proot et al., 2000a; 2000b; 2002); and good and accurate information or advice can enable patients and carers to make informed decisions (Alaszewski et al., 2008; Olofsson et al., 2005). On the contrary, lack of information from professionals inhibits patients' participation and puts constraints on their autonomy (Health Care Commission, 2006; Proot et al., 2000b; 2007). Equally important for making decisions is encouragement from professionals who promote patient autonomy (Proot et al., 2002). Conversely professionals who provide too much care to patients, hold a paternalistic attitude towards them and discourage them from making their own decisions inhibit participation (Proot et al., 2000a; 2002).

In terms of the impact of support from family, according to Proot et al. (2000a; 2000b), stroke patients experience increased decision-making autonomy during the rehabilitation process with strong support from their family members, who encourage patients to make decisions and hold positive attitudes towards patients' decision-making capabilities. Olofsson et al. (2005) found that when returning home following discharge patients required family support in order to return to active participation in making decisions. However, very high levels of family involvement in decision-making inevitably prohibited patients' participation during their rehabilitation process. For example, paternalist or overprotective families can control patients' decision-making (Proot et al., 2000a; 2000b; 2002). These findings are supported by the study conducted by Zhang et al. (2004) who found that some family members had inappropriate decision-making behaviours, taking control even when the person with the stroke was able to act independently.

Conversely, a lack of support, especially from professionals could severely reduce capacity for involvement in decision-making. Several examples were identified, including:

- o Negative attitudes and behaviours towards patients impeded patient participation: some doctors were perceived as uncaring and unconcerned, abrupt, not wanting to talk or knowing how to talk with patients, not wanting patients to participate and not wanting to be questioned. Some doctors did not take the time to explain or provide sufficient information to allow patient participation, or had an authoritative or intimidating manner (Belcher et al., 2006).

- Poor communication skills by doctors impeded patient participation (Belcher et al., 2006; Jewell, 1996).

- Overprotection of patients impeded patient participation (Belcher et al., 2006; Jewell, 1996).

- Taking a dominate role in decision-making: e.g. dominating a family meeting or making decisions for patients served as impeding factors for carers' participation in decision-making (Walker and Dewar, 2001).

- Not giving patients sufficient time to participate impeded patient participation (Belcher et al., 2006; Jewell, 1996).

- Unwillingness to seek information from carers impeded carers' participation in decision-making (Walker and Dewar, 2001).

There were of course a range of facilitating factors that could have the opposite effect and these are considered in more detail shortly.

Another important point to consider is the patient's clinical condition.

- Patients' condition/severity of illness

The general literature indicates that patients who are less ill prefer more active participation and have a more positive attitude towards patient participation in decision-making (Levinson et al., 2005; Henderson and Shum, 2003; Arora and McHorney, 2000; Biley, 1992). Health problems that require an urgent decision were reported as barriers to patients playing an active role in decision-making (Elwyn et al., 1999). This often pertains in the early stages of stroke.

The severity of a stroke patient's condition has an important effect on their decision-making capability (Proot et al., 2002). Patients who are more independent and better able to carry out activities of daily living were significantly more likely to want to participate in decision-making relating to care, rehabilitation, and discharge planning (Almborg et al., 2008). On the other hand Chang et al. (2004) suggested that patients' with a less severe condition were more likely to delay help seeking decisions ignoring the need for urgent medical care which might be a determining factor in the overall outcome.

In addition to the above a number of other factors could influence the degree to which patients, and to a less extent carers, were involved in decision-making these included the type of decision to be made and the nature of the organisation.

- Types of decisions

Mansell et al. (2000) reported that patients preferred to share major treatment-related decisions (radiation, chemotherapy, colostomy, and respirator use in cancer, temporary pacemaker and bypass surgery in myocardial infarction, and foot amputation in diabetes) or decisions about their own behavioural change (smoking, diet, and exercise) with their doctors. They wanted less involvement in minor decisions (laboratory tests, bed rest, checking blood glucose, increasing insulin, and special shoes in diabetes).

- Organisational influences

Biley (1992) reported that organisational freedom could facilitate patient participation. For example, in a hospital where there were more relaxed rules and more freedom of choice offered to patients, patients made more autonomous decisions, especially about their daily routines e.g. being able to receive visitors at any time in the day, and being able to decide when to get up and have a wash on their own rather than obeying nurses' orders. It was suggested that flexible routines allowed patients to have more choice and more opportunities to make decisions on their own. As a result, patients had more actual or perceived control over their environment and what was going on around them (Biley, 1992).

The literature cited above demonstrates that decision-making in a health care context is influenced by a variety of factors, including patient-related factors, professional-related factors, and other variables related to types of decisions that were made and the clinical environment. This highlights the complexity surrounding the nature of decision-making.

Many of the above factors highlighted the importance of the interactions between patients and professionals, especially doctors and it is clear that much could be done to promote involvement in decision-making.

Strategies used to facilitate patient and carer participation

In the general literature seven studies reported a range of strategies used by doctors, nurses, and patients themselves, which enabled patients to be more actively

involved in decision-making activities. The researchers found that in order to facilitate patients' active involvement in making decisions, doctors and other professionals needed to:

- Present and discuss information and options appropriate for patients of different ages and educational levels (Lown et al., 2009; Larsson et al., 2007; Elwyn et al., 1999);

- Explicitly encourage patient participation in decision-making, and help them to understand their right to take an active role (Sahlsten et al., 2009; Fraenkel and McGraw, 2007b; Larsson et al., 2007).

Similarly, nurses need to spend time working with patients (Larsson et al., 2007), help them to recognise and use their own strengths and resources to improve their self-care abilities, and to encourage, build up and preserve patients' self-confidence (Sahlsten et al., 2009). More importantly, both doctors and nurses should explore patient's preferences, opinions and experiences, by establishing a connection with them on a personal level (Zhang et al., 2010; Lown et al., 2009; Sahlsten et al., 2009; Larsson et al., 2007; Elwyn et al., 1999).

However, patients also have responsibilities. For instance, they should clearly express their preferences and needs (Lown et al., 2009), be aware of the uncertain nature of medicine and the necessity of making choices (Fraenkel and McGraw, 2007b; Larsson et al., 2007), and actively seek and receive information, support and help from professionals, families, and friends (Lown et al., 2009; Sahlsten et al., 2009; Larsson et al., 2007; O'Connor et al., 2003).

Studies located in the literature specifically relating to older people and their carers also identified a number of positive approaches. These are considered below.

Two studies paid particular attention to strategies that could be used by professionals to facilitate patients' or carers' participation in decision-making (Tutton, 2005; Walker and Dewar, 2001). A wide range of strategies which could enhance participation were identified, including:

- Allowing patients to lead the communication between them and professionals
- Providing patients and carers with information and allowing them to make choices

- Knowing patients' personal history, how they would like to live their daily life, and about their illness and dependency needs.
- Understanding and meeting patients' or carers' needs
- Establishing partnerships between patients/carers and health professionals (e.g. showing respect for the patient, trusting each other, negotiating care, and encouraging patients' control over their own activities)
- Establishing and maintaining an emotional connection between patients and professionals (e.g. accepting each other, and maintaining positive emotion)
- Viewing participation as a dynamic process which may progress and change over time
- Being approachable and maintaining contact with patients and carers

From the above it is apparent that concepts such as participation, involvement and partnership building are key elements of more informed decision-making. For instance, patients, doctors and nurses need to respect each other and reach a mutual understanding and commitment (Lown et al., 2009; Sahlsten et al., 2009; Larsson et al., 2007), and have a dialogue in order to agree goals for action (Larsson et al., 2007). Therefore it is suggested that doctors and nurses should view patients as a valued co-worker or an equal partner based on clearly defined expectations and roles (Lown et al., 2009; Sahlsten et al., 2009).

Based on the above findings, there are a wide range of strategies identified that can enhance patients' participation. However, it is clear that one of the most important strategies is to establish a relationship or partnership within which patients and professionals can effectively exchange information and discuss preferences, needs, and expectations with each other. Such dynamic two-way interaction and communication are widely recognised in the literature as promoting patient involvement in decision-making. Central to such relationships is the development of trust.

The role of trust in decision-making

Establishing and maintaining mutual trust between patients and doctors or nurses was highly valued in many studies in both the general decision-making literature and that relating to stroke. For instance, patients believed that trusting relationships facilitated their participation, enhanced their confidence, and made them feel more at ease when making decisions (Lown et al., 2009; Sahlsten et al., 2009; Smith et al., 2009; Larsson et al., 2007). Kelly-Powells (1997) found that when doctors were

seen to make an accurate diagnosis then patients would be more likely to accept the treatments they recommended.

Zhang et al. (2008) indicated that difficulties in establishing a trusting doctor-patient relationship was one of the major barriers to patient participation. When patients did not trust their doctor then they preferred to rely on their own judgements when making decisions (Fraenkel and McGraw, 2007b).

However, when trust was established differing outcomes resulted. For example, patients in Rotar-Pavlič et al.'s (2008) study described participation in health care decision-making as a mutual activity and a relationship based on trust between themselves and doctors which improved their treatment outcomes. Conversely, the study of Belcher et al. (2006) suggested that trust could actually reduce participation. Therefore patients who reported trusting their doctor were more likely to accept the doctor's decisions and follow his or her advice rather than make decisions on their own (Belcher et al., 2006).

Interestingly a lack of trust in some studies encouraged patients to make their own decisions. In the study undertaken by Rydeman and Tornkvist (2009) patients and carers tended to be more actively involved in decision-making when they distrusted their professionals' information and choices. In such instances they would actively check information with other physicians, nurses or pharmacists, or search for information in books or other written materials. This is analogous to the 'seeking' activity described earlier.

These conflicting findings suggested that trust in professionals can be considered as both a barrier and facilitator to patients' or carers' participation in decision making. The behaviours driven by the trusting relationship between patients/carers and professionals might vary from person to person, further highlighting the complexity of the decision-making processes and relationships between patients, families and professionals.

The role of trust in stroke care

The literature also clearly indicates that trust plays a critical role in decision-making with stroke patients and carers and was closely linked to better compliance, more active participation and positive outcome. Conversely, lack of a trusting relationship between professionals, patients and carers could lead to negative

consequences and damage their cooperation. However, there was relatively little information about the nature of the trusting relationship between patients and family carers and its impact on their decision-making behaviours.

For example, Alaszewski et al. (2008) suggested that it was easier for stroke patients to decide to comply with or accept medication when they trusted professionals. In Slingsby's (2006) study, professionals were found to consider a trusting relationship between them, patients and families as the most important factor influencing patients' participation in rehabilitation and their rehabilitation outcome.

More specifically, Slingsby (2006) found that, whether a stroke patient was motivated or not was in large part determined by the degree to which he or she trusted professionals. Patients who trusted professionals were reported to have a sense of security, have a strong motivation for rehabilitation, cooperate well with professionals, actively participate in rehabilitation and have a better rehabilitation outcome. Even 'uncooperative' patients began to develop an enthusiasm for rehabilitation once a trusting relationship was developed between them and professionals. However, lack of trust could lead to negative consequences. For example, family members who had a lack of trust and were unhappy with the hospital and professionals would decide to leave the hospital and require a discharge.

In terms of the conditions for trust, the study suggested that in order to develop a trusting relationship between them and stroke patients, professionals often adapted their behaviour and communication style based on what worked best with each individual patient (Slingsby, 2006). This suggested that if professionals tailored their behaviour and communication style tailored to patients' needs then this was potentially the key to establishing trust. For example, it was found that therapists, nurses and doctors would communicate and behave differently with a patient who was introverted and stubborn, or who was outgoing and enthusiastic about rehabilitation, depending on what seemed appropriate for each patient.

Summary

In summary, the literature on health care decision-making identified a diverse range of factors influencing the decisions that were made. Decision-making across health encounters was described as a dynamic process which patients and health

professionals ideally worked together to reach a decision. From the studies described in this review, there was consistent evidence of the complexity of patient participation in health care decision-making, in which, patients had different levels of preference about participation. Differences were also apparent between patients' preferences, patients' actual role and nurses' perceptions of patients' preferences suggesting that nurses might not be able to accurately identify patients' preferred level of participation and meet their specific needs.

These findings suggested that nurses, as well as other health professionals, need to make a thorough assessment of individual patients' preferences for participation through effective communication with patients (Wellard et al., 2003), so as to ensure the patient's preferred level of participation and to improve their satisfaction with participation in decision-making (Lam et al., 2003).

Different factors were reported as either facilitators or barriers for patients' participation, and included:

- Patient-related factors (such as patients' age, gender, education level, relationship between patient and professionals, severity of illness or degree of wellness and physical fitness, and how well informed patients were);

- Professional-related factors (e.g. doctors' poor information provision for patients, lack of time spent with patients, poor interpersonal communication skills and a lack of experience in involving patients in decision-making);

- The type of decisions being made and organizational factors.

The findings from a number of studies identified a variety of strategies used by doctors, nurses, and patients themselves, that could help patients to be actively involved in decision-making activities.

There was clear evidence that decision-making varied over time and that the development of trust played a central role in health care decision-making and relationship between patients and professionals. In addition to trust other key concepts included participation, negotiation and partnership. Participation was most commonly used to characterise the role which patients played when making their health care decisions, only a small number of studies did not explicitly use the concept of participation (Deber, et al., 2007; O'Connor et al., 2003; Kelly-Powell,

1997). Thus it seems shared, rather than autonomous decision-making, is the preferred option in many cases. However, it must not be forgotten that in a number of studies patients or carers preferred a passive role.

The review also highlighted the importance of negotiation in patients' decision-making processes. For example, Lown et al. (2009) and Smith et al. (2009) reported that in order to facilitate shared medical decision-making, patients and doctors needed to acknowledge aspects of agreement and disagreement and negotiate a decision. Similarly, the need for patients, doctors and nurses to work in partnership was also consistently emphasised. Partnership building was also identified as an important strategy to facilitate patient participation in decision-making. For instance, patients, doctors and nurses need to respect each other and reach a mutual understanding and commitment (Lown et al., 2009; Sahlsten et al., 2009; Larsson et al., 2007), and have a dialogue in order to reach an agreed goal for action (Larsson et al., 2007). Therefore it was suggested that doctors and nurses should consider patients as a valued co-worker or an equal partner based on clearly defined expectations and roles (Lown et al., 2009; Sahlsten et al., 2009).

The role of the family carer in decision-making was more frequently mentioned in the context of stroke and the principles identified above area also relevant to family carers. However, there was less explicit recognition of the important role of family carers by professionals and they were often left 'seeking' for information, advice, support and for recognition of their potential contribution (Brereton and Nolan, 2002; 2003).

It is important to note that the vast majority of the above literature emerged from studies in Western cultures and health care systems. Here the language of participation and involvement has been a major driver in terms of the academic, policy and practice literatures for many years (Nolan et al., 2007). Whether concepts such as participation, partnership, involvement and negotiation play such a prominent role on Chinese culture remains to be seen. This was the driver for the second review on the role of culture in health care decision-making.

The Role of Culture in Health Care Decision-Making

As already noted decision-making is an integral component of health care for professionals, patients, and family carers (Epstein et al., 2004; Nordgren and Fridlund, 2001) and culture is likely to have a significant influence decision-making

(Leininger and McFarland, 2002). It is the nature of this influence that the section seeks to explore. Themes that were distilled from the literature were:

- The key part played by the family
- The balance between interdependence and independence
- Relationship-centred decision-making style

<center>The key part played by the family</center>

The literature indicated that from a cultural perspective family members play a highly influential role in health care decision-making. A total of nine studies explored topics such as how patients made medical or end of life decisions, the extent to which doctors involved families in making end of life decisions, patients', family members' and doctors' attitudes towards disclosure of the diagnosis or prognosis and how family members' cultural beliefs impacted on their decisions.

For example, Hattori et al. (2005) investigated older patients' preferences and wishes for end of life care in Japan. They indicated that where to die and the potential care burden for family members were identified by Japanese older patients as an important consideration when they made end of life decisions. Most participants wanted to die at home with family members at their bedsides. However, as they were concerned about burdening family members some participants gave up their expectation to die at home, reflecting family influences on Japanese patients' end of life decisions.

Huang et al. (2003) in the US found that compared with white counterparts, Chinese older people were less likely to make medical decision by themselves and more likely to depend on family members for decision-making. However, no significant differences were found between Chinese, Hispanic, and black older people. Such racial or ethnic differences might be due to the family-centred decision-making style held by Chinese and other minority groups, which is different from the white participants' decision-making model that valued patient autonomy (Hornung et al., 1998; Blackhall et al., 1995).

A questionnaire survey carried out by Yap et al. (2004) in Hong Kong suggested that the majority of doctors working in intensive care units preferred to involve families when making decisions concerning limiting therapy. However, less than half of the doctors in a European study involved families in their decision-making

process (Vincent, 1999). This strong preference for family participation in decision-making probably reflects Hong Kong doctors' respect for the Chinese cultural tradition which emphasizes family values and the families' leading role in health care decision-making for patients (Ip, 1998). In such a strong family-centred society, health care decision-making is recognized as primarily the responsibility of family members.

Reflecting similar beliefs, Elwyn et al. (2002) reported that in a Japanese cultural context, doctors do not disclose a diagnosis of cancer to patients, believing that it will depress them. They therefore inform the family first and leave the decision as to whether to tell the patient or not to the family. Most families did not wish the patient to be told and therefore they remained uninformed. It was suggested that physicians were following the Japanese tradition of letting the family make important health care decisions.

Similar findings on the disclosure of a cancer diagnosis were reported by Ruhnke et al. (2000) in a questionnaire survey comparing the attitudes towards decision-making autonomy of physicians and patients in Japan and the US. The results indicated that more US physicians and patients than their Japanese counterparts agreed that a doctor should inform patients of an incurable cancer diagnosis first and then ask them to decide whether their family should be told. In contrast, more Japanese physicians and patients than their US counterparts thought that a doctor should inform families of the diagnosis of an incurable cancer first and then let them decide whether the patient should be told. This study demonstrated significant cross-cultural differences about decision-making and truth telling in terminal cancer, in which the US sample favoured patient autonomy, whilst the Japanese sample emphasized family authority. The researchers suggested that the differences between the Japanese and the US samples were determined by the different cultural characteristics in both countries. The US decision-making style resulted from a culture favouring and advocating patient autonomy. However, in a Japanese cultural context, in order to respect family authority, open discussion with the patient was not acceptable (Hoshino, 1995) highlighting the dominant role played by the family as opposed to the individual. Similar findings have been found in Taiwan (Tang et al., 2006) and Korea (Yun et al., 2004) suggesting that in an Asian cultural context family members expect to be informed about a cancer diagnosis and its prognosis prior to the patient. Whilst these findings were true for doctors and families across these countries, patients' views varied.

For example, Tang et al. (2006) in Taiwan found that cancer patients much preferred their physicians to inform them about the diagnosis and prognosis rather than their families. Similarly, Yun et al. (2004) in Korea found that 78.3% of patients thought that the doctor in charge should inform patients about a cancer diagnosis, and 71.7% of patients thought that patients should be informed immediately after the diagnosis. The findings from both of these studies suggest that Taiwanese and Korean cancer patients have similar information needs and preferences for truth telling about their diagnosis and prognosis as their Western counterparts, such as those in the UK (Benson and Britten, 1996) and the US (Marwit and Datson, 2002). However, in contrast, Japanese patients wanted family members to be informed first and showed stronger preferences for family authority rather than patient autonomy when compared with their American counterparts (Ruhnke et al., 2000).

It was interesting that patients from Asian countries have different attitudes towards truth telling, highlighting the complexity of cultural influences on decision-making. Therefore, caution needs to be taken when families and professionals care for cancer patients from Asian cultural contexts who may have different information needs and desired roles in making decisions.

The only study identified from mainland China (Cong, 2004) examined doctor-patient relationships and who should be told potentially 'bad news'. It was found that the majority of doctors preferred to inform family members first, and believed that the family should decide whether, what, and how much the patient should be told. Families would provide information if they thought the prognosis was good but would withhold information or even lie if it was poor. These findings suggest that family members play a dominant role in decision-making, reflecting the traditions of ancient China, where family members take the decision-making role for the patient. However, patients in the same study had different preferences for making decisions. Some desired more autonomy and wanted to make decisions on their own. In contrast, some patients felt that they were old and should follow their children's decision, reflecting the Confucian point of view, in which older people do not assume an independent role but pass their responsibilities on to their adult children. Some patients reported that being cared for and having all the decisions made by their family made them happy. The researcher suggested that this was perhaps because in the duty-oriented tradition in China, family and society are supposed to relieve older people of most responsibilities.

Consequently, family members made treatment decisions and signed the informed consent form for their relatives. The researcher argued that the model guiding the current practice of informed consent in China is based on a 'doctor-family-patient relationship', reflecting the families' dominant role in decision-making within Chinese traditions. Such beliefs also influenced the type of treatment that a patient might receive. For example, most Taiwanese carers often decide to use traditional folk care, especially food therapy and TCM, to improve body energy to deal with side effects of Western medicine for cancer treatment (Liang, 2002).

Based on the findings from the above studies, it is clear that families play the major, or even the only, role as decision-makers, even if this might run contrary to the patient's wishes. This suggests an enduring and pervasive set of cultural beliefs that may be highly influential in the present study. It also suggests that there is a different balance between dependence, interdependence and independence operating between Western and Eastern health care decision-making, potentially questioning ideals such as autonomy.

The balance between interdependence and independence

Deeply-rooted cultural beliefs clearly exert potentially significant influences on peoples' health care decision-making behaviours (Ngo-Metzger et al., 2004). For example, Bowman and Singer (2001) found that Chinese older people trusted their children's decision-making abilities and would leave their end of life decisions (e.g. decisions related to forgoing treatment such as, life support ventilation for the patient, advance care planning and advance directives) up to their children when they were no longer able to make these decisions themselves. It has been suggested that this is because Chinese culture emphasises interdependence (Lee, 1991) as well as intergenerational responsibility (Tsai, 1999; Berger, 1998), and that children should support their older parents.

Furthermore, according to Lee (1991) the value placed on interdependence means that decisions are seen as 'belonging to the family' rather than any individual. Since integrity is highly valued, members of the family are expected to maintain rather than disrupt family harmony so do not promote independence and individuality. Therefore, harmonious familial relationships are maintained through fostering interdependence and conformity and minimizing conflict within the family unit.

In contrast, Western culture emphasises individuality and independence, therefore promoting a degree of autonomy in decision-making that might not be appropriate in other cultures (Wang and Marsh, 1992).

<center>Relationship-centred decision-making</center>

Findings from four studies highlighted that patients as well as doctors often adopted a relationship-centred decision-making style. For example, patients with an Asian cultural background tried to create and maintain a harmonious relationship with their family members, friends, as well as professionals when making various health related decisions. Similarly, Japanese doctors were also found to try to reach consensus and maintain a harmonious relationship with family members when facing decision about disclosing cancer information to their patients.

Takahashi et al. (2003) found that in Japan the family plays a major role in a variety of health-care decisions. For example, acceptance of an influenza vaccination required recommendation by family and/or a close friend and having family and/or friends who had previous vaccination experiences. However, patients in the US and other western countries usually made health care decisions on their own and family and friends were not significant determinants in accepting an influenza vaccination (Van Essen et al., 1997).

The researchers suggested that this might be due to the importance of the family's decision-making role in Japanese cultural tradition. Therefore, in contrast to the dominant 'autonomy-type ethical orientation' adopted in the US and other Western countries, people in Japan or other Asian countries emphasise a 'relation-type ethical orientation' (Ohi, 1998), in which maintaining harmonious relationships with family or friends is considered to be the most important factor.

Ngo-Metzger et al. (2004) explored how Asian culture influenced patients' perceptions of the extent to which doctors involved them in health care decision-making in the US. They found that Asian Americans (i.e. participants who were Chinese, Filipino, Asian Indian, Japanese, Vietnamese, and Korean) were more likely to report that the doctor did not involve them as much as they would have liked in health care decision-making compared to white Americans. It was suggested that this might result from cultural differences in communication style between Asian and American people. For instance, Asian people often showed respect for doctors and their authority by nodding and smiling in order to maintain a

<center>53</center>

good relationship with doctors (Kagawa-Singer, 1996). However, this was often misunderstood by the doctors as agreeing with them. Furthermore, even if they did not agree, Asian patients would be less likely to openly question the doctor (Mull et al., 2001).

According to Bowman and Singer (2001), the Chinese tradition of maintaining harmonious interpersonal relationships strongly influences older patients' decision-making behaviours. For example, in order to maintain a harmonious familial relationship, older patients were unwilling to designate a surrogate decision-maker due to the concern that conflicts within the family might develop if there was disagreement between the surrogate decision-maker and other family members. They believed that consensus amongst their adult children was important in ensuring good decision-making.

In Ruhnke et al.'s study (2000), one of the possible reasons why Japanese doctors preferred to disclose a cancer diagnosis to family members rather than patients was also due to the importance of maintaining harmony in Japanese culture. In order to avoid disrupting harmony and promoting consensus between them and family members, doctors would respect family authority and refuse to have an open discussion with patients about their cancer diagnosis (Hoshino, 1995).

The idea of maintaining harmony in relationships results in a 'relational type ethical orientation' (Ohi, 1998) that stands in marked contrast to current beliefs and practices in Western contexts that promote autonomy as the guiding value in health care.

Summary

In summary, findings from the above studies demonstrated the significant role of culture in influencing patients', families' and professionals' health care decision-making practice in a broad range of situations. The literature on the role of culture in health care decision-making identified several key themes that could help to inform the present study, such as interdependence, harmony and relationship-centred ethics. In particular the importance of a family-centred decision-making model could well be highly influential and resonates with my own experience described earlier.

It seems that the Chinese cultural ideal of valuing interdependence as well as intergenerational responsibility still strongly influences people's decision-making behaviours, especially amongst older people who often leave their health care decisions up to their adult children. A relationship-centred decision-making style was also commonly practiced amongst patients and doctors of Asian origin, who considered maintaining a harmonious relationship between patients, family members and professionals as the most important goal. Similarly, in the area of stroke care Slingsby (2006) suggested that Japanese health professionals prioritized family relationships over patients' decision-making autonomy and families' decisions over stroke patients' decisions.

Conversely, not all studies demonstrated consensus and in some instances patients wanted to play a greater role in decision-making than they were permitted to by their families and doctors. It is possible that this trend will accelerate as Western values and beliefs become more common in Eastern cultures. Therefore, there is a need to further research exploring the complex influences of culture on health care decisions and this is an aspect that will inform the current study.

Sensitising Concepts and Foreshadowed Questions Guiding the Study

As has already been noted the role of the literature n GT remains contested and it is important that in any given study the role the literature played is made explicit. In this study, which adopted a constructivist approach to grounded theory (Charmaz, 2006 see later), the literature review was intended to identify and number of potential sensitizing concepts that would shape the initial foreshadowed questions (Rodwell, 1998). Two distinct but related searches were conducted. The first explored the nature of decision-making in health care in general, for older people and their carers and in stroke. Initially three separate reviews were conducted but because of the similarity in the results these were synthesized. A second review was undertaken to explore the role of culture in decision-making.

Both identified decision-making as a highly complex process. The largely Western literature on decision-making identified a range of sensitising concepts which suggested that decision-making is a complex process that may vary over time and that this is influenced by a number of patient, carer and professional factors. It is seen as a process rather than an event but that central to it are ideas concerned with partnership, negotiation and involvement, the degree of which will vary depending on factors such as personal preferences and the timing and nature of the decision.

The role of the family in decision-making, whilst an emerging area of study, was not yet fully developed.

The literature on the role of culture in decision-making again highlighted the complexity of the issue involved but questioned many of the assumption in the wider literature and it was noted that there was a much greater role for the family, who were often the primary, and occasionally the only, party involved in decision-making. It was apparent that long-held cultural beliefs to do with relationships, harmony and family responsibility continued to exert a highly significant influence, even if sometimes the patient wished for a more active role. With these considerations in mind the following initial foreshadowed questions guided the early part of the study:

- What are the processes of decision-making that operate in acute stroke settings in China and do these change over time?
- What factors influence decision-making?
- What types of strategies are used when making decisions?
- What types of decisions are made and when?
- Who is usually involved in decision-making?
- What is the role of culture in decision-making?

CHAPTER 4: METHODOLOGY

Introduction

The overall aim of this study was to explore the nature of decision-making processes that occur between people with stroke, their family carers and professionals in an acute care context in China. Based on a consideration of the literature the study sought to address a number of foreshadowed questions, as illustrated below:

- What are the processes of decision-making that operate in acute stroke settings in China and do these change over time?
- What factors influence decision-making?
- What types of strategies are used when making decisions?
- What types of decisions are made and when?
- Who is usually involved in decision-making?
- What is the role of culture in decision-making?

However, I did not just want to add to knowledge but also produce insights that might help older people and family carers to play a full part in the decision-making process. As will be explained below this desire guided me towards the use of a constructivist GT approach.

This chapter justifies the use of a constructivist GT approach to the study and explores how I applied the principles in practice. It begins with a consideration of why a qualitative method was selected, then discusses why a GT approach was selected. Subsequently, the tenets underpinning GT and constructivist GT in particular are outlined before attention is turned to the conduct of the study, the ethics involved and the quality criteria to be used to judge the robustness of the study and its product.

Qualitative or Quantitative Approaches: Which to Use?

Broadly speaking research methods fall into two main groups, quantitative and qualitative approaches and researchers have long debated the relative merits of differing traditions (Patton, 2002). Both qualitative and quantitative researchers "think they know something about society worth telling to others, and they use a variety of forms, media and means to communicate their ideas and findings"

(Becker, 1986, p. 122). However, the approaches differ in important ways: philosophically and methodologically (Denzin and Lincoln, 2005). At the most fundamental level debates centre on the nature of reality, how we can comprehend it and what is the most appropriate way to study it. Such debates help to demarcate differing paradigms of research.

A paradigm is basically a world view or a "set of propositions that explain how the world is perceived" (Sarantakos, 1993, p. 30). Guba and Lincoln (1994) suggested that research paradigms can be differentiated dependent on how they address three basic philosophical questions (p. 108):

- The ontological question: what is the nature of reality?
- The epistemological question: what is the nature of the relationship between the inquirer and the known?
- The methodological question: how can the inquirer gain knowledge of the world?

The selection of the research approach adopted is dependent not only on the nature of the question being asked but also upon the paradigm of inquiry which is held by the researcher. For example, qualitative research uses a naturalistic approach that seeks to understand individuals' personal and social experiences, processes, their meanings and purposes in context-specific settings. It aims to provide rich descriptive accounts of the phenomenon being researched and explanations about human behaviours and is more flexible in its research design. As such, reality is viewed as being socially constructed and context specific, knowledge being the product of interactions between people. Conversely, quantitative research uses largely experimental methods, quantitative measures, variables, numbers and statistical procedures to seek causal determination, prediction and test hypothetical generalisations which are context free. As such, reality is seen as largely pre-determined, with knowledge comprising 'universal laws' which are held irrespective of the relationships between people (Denzin and Lincoln, 2005).

Generally speaking, qualitative approaches are best applied in situations where relatively little is known about the subject of study, when the questions under consideration involve an understanding of the meanings people bring to bear and circumstances are likely to be influenced by context and interactions (Munhall, 2007). This was clearly the case in respect of the present study and therefore a qualitative approach was deemed the most suitable. This was further reinforced by Benoliel (1984) who suggested some time ago that the nature of decision-making

processes is one of the broad areas in nursing research where qualitative approaches appear likely to be especially fruitful. However, qualitative methods are numerous and it was important for me to select the most appropriate one for this study.

Considerations Informing the Use of Constructivist GT Approach

Selecting the most appropriate design among a variety of different qualitative research methods and traditions and applying it to a research project depends upon the extent to which the research method is able to investigate the research questions and achieve the purposes of study (Denzin and Lincoln, 2005).

According to Denzin and Lincoln (2005), there are three main types of qualitative study, i.e. ethnography, phenomenology and GT. However, in addition to these three approaches, there are a range of other approaches including case study, life history, historical method, action and applied research and clinical research.

Consideration was given to all of these but most attention was paid to the three main approaches which tend to address different types of questions. For example phenomenology, which was derived primarily from philosophy and psychology, mainly looks at "meaning" questions and tries to elicit the essential meaning of an experience for participants. By contrast, ethnography which originated from anthropology, is interested in answering descriptive questions around issues such as values, beliefs and practices of a particular cultural group within a given context (Denzin and Lincoln, 2005; Morse, 1998b, p. 63). Neither of these approaches seemed to address the central issue in the present study, which was to understand the **processes** of decision-making following stroke from the perspectives of multiple participants. Grounded Theory, which was developed from sociology, seemed particularly well suited since it primarily deals with 'process' questions and experiences over time and attempts to inductively develop a theory which is grounded in data and also has the potential to inform ways of generating action to, if necessary, alter the way that processes act in the social world (Glaser, 1998).

Essentially the purpose of GT is to develop and build a mid-range theory (Glaser and Strauss, 1967) which, when compared with 'grand' theories from the quantitative tradition: use less abstract ideas to explain a more limited number of variables in particular situations; focus on practical issues; and can be more easily applied by practitioners in diverse contexts. Theories which look at a particular issue in a given context are termed 'substantive' theories. Subsequently, making

comparisons between the newly developed theory, existing knowledge and the wider literature can broaden its scope or the range of phenomenon that the theory attempts to explain, resulting in the development of a formal theory. The goal here was to develop a substantive theory in relation to decision-making in acute care in China.

Charmaz (2006) suggests that GT not only generates rigorous knowledge to inform and guide professional practice, but also aims to make changes to improve practice. My main intention within this study was not only to develop a mid-range theory of decision-making with older patients and their family carers in the context of stroke, but also to produce new knowledge that would be accessible to and valued by participants. Given the main purpose of the study, a GT approach seemed highly appropriate and provided a methodological framework guiding the research process.

GT principles guide the researcher in the design and process of collecting and interpreting data, of discovering categories and concepts to build theoretical frameworks, and to develop theory that is truly grounded in the data (Glaser, 1998). However since its 'discovery' (Glaser and Strauss, 1967) a number of variants of GT have emerged and it is important to understand the method that I applied.

GT is underpinned by symbolic interactionism (Annells, 1996) which is predicated on the belief that human behaviours occur within a social context and are influenced by socially derived concepts such as self, other and group (Mullen, 1986). Researchers who use symbolic interactionism as a theoretical framework to conduct their studies need to study not only human behaviour, but also the influences of other factors, such as culture (Denzin, 1989).

What interests grounded theorists are phenomena as experienced in the everyday social world and the basic social processes underlying these phenomena, that is to say, social problems or situations which people encounter and the basic processes that people use to deal with these problems or situations (Benoliel, 1996). Symbolic interactionism argues that reality is not static, but undergoes constant change as people interpret their world (Porter, 1991). In order to understand human behaviours, grounded theorists need to investigate and explain the interpretative and interactional processes that shape an individual's behaviour. However, how they do this varies according to the broad approach to GT that is adopted.

Charmaz (2000; 2006) argues that the GT method has evolved into two major different forms, i.e. objectivist and constructivist GT, since it was initially developed by sociologists Barney G. Glaser and Anselm L. Strauss in their seminal work, 'The Discovery of Grounded Theory' (1967). Charmaz (2006) explicates the differences between the two approaches, and suggests that objectivist and constructivist GT method reside in two different inquiry paradigms respectively, i.e. positivism and constructivism paradigm of inquiry.

Charmaz (2006) sees Glaser and Strauss's original formulation as being primarily positivist in approach. Consequently, objectivist grounded theorists assume that data represent objective facts, which are 'found' by the researcher, and from which the researcher 'discovers' theory. During the research process, researchers act as unbiased and outside experts who remain relatively separate and distant from participants and their world and ignore the social context, their own influence, and interactions between participants and themselves (Charmaz, 2006).

In contrast, Charmaz (2006) promotes a much more interactive and engaged approach in which the researcher and participants jointly 'construct' their understanding of reality and in which the researcher, far from being distant and detached, plays a key role in shaping the emergent theory with the participants. As I wished to engage fully with participants and recognized the role that my own experiences and feelings would play in shaping the theory I opted for a constructivist model.

Constructivist GT provides a means for people to better understand reality and in order to do so has several important characteristics, namely: an emergent research design; an holistic and inductive perspective; employs theoretical sampling and constant comparison and seeks to recognise and account for any preconceived biases. These are explored in more detail below.

Emergent Research Design

According to Lincoln and Guba (1985), the research design within a constructivist approach involves, "planning for certain broad contingencies without however, indicating exactly what will be done in relation to each" (Lincoln and Guba, 1985, p. 226). Thus, as noted by Rodwell (1998), it is inappropriate to determine the exact research process in advance, rather the researcher adapts the research method as the study progresses. Although careful consideration was given to the research design

when I initially planned the study, adopting a constructivist GT method required me to start with a general approach rather than a detailed and fixed set of procedures. The study design needed to be flexible enough to allow for potential modification, not only to method but also to the focus of the study, in order to accommodate new information or issues which might emerge as the study proceeded.

For example, originally the study was intended to focus mainly on participants' decision-making experiences during the two week acute hospital stay. However, after the initial interviews it was clear that a wide range of experiences were important to a full understanding, for example events that occurred prior to admission or after discharge, experiences of having other types of health problems, or experiences of having multiple episodes of stroke. An emergent design is therefore essential to meet one of the central tenets of GT, theoretical sampling (see below). Later decisions were informed by preliminary findings from initial data analysis. This adjustment to the focus of study as the study progressed is entirely consistent with the methodological principle of emergent design in constructivist inquiry (Rodwell, 1998).

Adopting a Holistic and Inductive Perspective

In order to explore daily life, constructivist GT studies are carried out within an uncontrolled, naturalistic setting in which realities are holistic and cannot be understood and interpreted in isolation from their contexts (Glaser, 1998; Rodwell, 1998). The phenomena under study and the context where the phenomena take place are all relevant and regarded as central to the research question itself (Hinds et al., 1992). Consequently, as Leininger (1994) advises, one must comprehend data from a holistic perspective using an inductive approach to comprehend, explicate and develop theory (Strauss and Corbin, 1990). Inductive data analysis is one of the important methodological requirements of constructivist inquiry (Rodwell, 1998). However, equally important within constructivist GT is that participants themselves play a key role in the analysis process. This is something that is discussed in more detail later.

Theoretical Sampling

Whether using objectivist or constructivist ground theory, theoretical sampling is integral to GT (Charmaz, 2006). The aim of theoretical sampling is to select participants, situations or future questions asked on theoretical grounds that are

informed by prior analysis of existing data. During the data collection process, the researcher concurrently collects and analyses data and makes decisions about what data will be collected next and where to collect it (Glaser, 1998; Glaser and Strauss, 1967), whereby the preliminary findings of the emerging analysis shape the subsequent data collection process.

In this study, ongoing theoretical sampling was intimately linked with the concurrent data collection and analysis (see constant comparison below), and was guided by the developing categories and emerging theory. It is important for grounded theorists to ensure that sampling is as open as possible to allow a variety of different situations or phenomena to be explored at the early stages of the research process. Afterwards, based on the findings that emerge during data analysis, sampling criteria as well as the interview guide, will be informed by the unfolding theory, and additional samples are shaped in order to test or verify the emerging theory (Yin, 1989; Strauss, 1978).

Adequacy is an important principle guiding qualitative sampling method, which indicates that there is an adequate amount of data to generate a thorough understanding and develop a full description of the phenomenon being studied. Ideally the point of data saturation should be achieved (Morse and Richards, 2002). Data saturation has been defined as occurring when, "no additional data are being found whereby the (researcher) can develop properties of the category. As he (sic) sees similar instances over and over again the researcher becomes empirically confident that a category is saturated" (Glaser and Strauss, 1967, p. 61).

In other words, when no new information about the participants' experiences or the phenomena under study emerge during the interview process and the researcher is satisfied that a rich and thorough understanding of the research question has been generated and an integrated and testable conceptual framework has been developed to explain the problem, theoretical saturation is reached (Morse, 2000; Stern, 1994). More recently, authors such as Charmaz (2006) have questioned whether you can ever truly know if saturation has been reached as the next interview may reveal new and important insights. However, data collection has to cease at some point and decisions about probable saturation are needed.

Constant Comparison

In addition to theoretical sampling, constant comparison is another central feature of GT (Charmaz, 2006). Within the GT research process there is ongoing and simultaneous data collection and analysis, which are closely connected and interact at every stage of the research process in order that the theory is generated and grounded in the data. This requires the use of constant comparison or constant comparative analysis method (Charmaz, 2006).

Constant comparison suggests that the interview be transcribed and analysed immediately after it is finished and preferably earlier than the second interview with the same (or differing) informant, because the emerging information or findings generated from the data analysis process should inform subsequent interviews as well as the further data collection. During this process there is a 'constant comparison' between and across participants, categories, themes and incidences. By using this analytical strategy, each piece of datum is compared with each other piece of related data and the data should be examined closely for all cases of phenomena which seem to be similar, either within the interviews with the same informant, or across the interviews with different informants (Glaser and Strauss, 1967). Concepts identified during data analysis and ideas emerging from the data are also compared with each other and between various cases, in order to establish commonalities and differences, develop and refine themes and later generate a GT with regard to a given research area.

In GT, theoretical sampling and constant comparison are also closely linked and this helps to ensure not only the appropriateness and adequacy of the sample, but also that the emerging theory is further tested and verified by recruiting additional samples (Yin, 1989).

Recognition of Preconceived Biases

During the inductive processes of qualitative inquiry, the researcher has to recognize and acknowledge any preconceptions, predetermined viewpoints, earlier conceptual hypotheses and even potential prejudices regarding the phenomenon under study, in order to let the data shape the discovery of categories. Therefore, whilst the researcher will enter the field with some sensitizing concepts and foreshadowed questions identified from the literature and their prior experience they must nevertheless be open-minded and sensitive to the data and what might be

uncovered within the data (Charmaz, 2006).

As noted earlier, (see literature review chapter) because of this the role of the literature review in GT is a source of some contention. Glaser and Strauss (1967) suggest that the literature should not be consulted until after data collection is completed whereas others argue that researchers should refer to earlier work appropriately and carefully (Morse, 1998a; Bartlett and Payne, 1997; Pandit, 1996; Chenitz, 1986). The researcher should not use the literature to presuppose categories which should emerge from the data (Strauss and Corbin, 1990). Morse (1994) advocates that a good understanding of existing work is necessary to avoid reinventing the wheel and that this knowledge should be used to allow the researcher to, "recognise leads but not be led" (p. 27). This was the stance adopted in this study.

Ethical Considerations

This project was formally approved by the ethics review procedure of the School of Nursing and Midwifery (Appendix 8), which was monitored by the University of Sheffield's Research Ethics Committee. Permission to conduct the study in the teaching hospital was also granted by the hospital's administrators after examination and discussion of the purpose and procedure of the study (Appendix 9). The teaching hospital was assured that their name and those of the staff would not be directly identifiable in any published report.

Long and Johnson (2007) argue that all research can be potentially harmful to participants, therefore it is important that researchers take effective strategies to reduce risks and meet health and safety requirements and that participants are fully informed of any potential harm related to their participation in the research. According to the research ethics guidance for nurses (Royal College of Nursing, 2009), the following issues must be addressed prior to the research commencing: informed consent; confidentiality; data protection; right to withdraw; potential benefits and potential harm.

In this study, all participants received written information about the purpose and methods used in the study and the voluntary nature of their participation (Appendix 10-11). All the participants had the right to withdraw from the study at any time without detriment to the care they receive. Assurance regarding anonymity was also given. In order for the older stroke patients to be able to easily read the written

information, I used a large font size in these written documents.

Although I received the signed written consent from the participants (Appendix 12), as participants would be interviewed on more than one occasion informed consent was seen as a dynamic and ongoing process between myself and the participants (Seymour and Ingleton, 1999).

According to Data Protection Act (UK Parliament, 1998), all confidential data should be safely stored in a locked cabinet, with authorised access only. Therefore the signed consent forms, together with the recorded interviews, observation data, and the list that identified the participants' pseudonyms were stored in a locked file with access restricted to myself alone.

The participants were also assured that participation would cause no harm to them and offered the opportunity to ask questions and discuss their concerns about the study with me at any time. Whilst there were no immediate benefits for the participants, their participation would help to contribute to an increased knowledge and in-depth understanding of the experiences of decision-making of older patients with stroke and their families during their acute hospital stay. It was hoped that the findings would help to ensure older patients with stroke and their families received high quality health and social care that ultimately improved their quality of life.

It was recognized that participants might experience slightly anxious feelings due to discussion about such topics as the circumstances of the stroke and its consequences, the health conditions leading to the admission and their experience with the different aspects of health care services, which might be painful and possibly distressing for some participants. However, they were free to choose not to respond to any questions and also free to stop the interview or the recorder at any time and it was carefully explained that if they chose to do so that this would not affect the care or treatment they were receiving.

Nevertheless, within the context of the Chinese culture thought had to be given to some potentially delicate issues. According to the traditional Chinese belief which dates back to the time of Confucius, talking about death, dying or serious disease can bring bad luck and may cause actual harm (McLaughlin and Braun, 1998). Therefore, talking about these topics to older patients would be potentially considered as negative and unethical (e.g. impolite, rude, or unacceptable). Therefore, instead of approaching patients, I carefully asked carers a series of

hypothetical questions in order to gain insights into patients' perspectives, e.g. whether patients would want to know the truth or bad news if they had a serious diagnosis or health condition, whether carers would want to know the truth if they had a severe stroke and how carers would make decisions if they themselves were patients with a severe stroke.

In addition, observational research (see later) in particular with older patients who are frail and vulnerable, raises important and challenging ethical issues that have to be considered by the observer in terms of informed consent and avoidance of potential harm (Higgins, 1998). As Stake (2008) points out, "qualitative researchers are guests in the private spaces of the world. Their manners should be good and their code of ethics strict" (p. 140). First, I needed to inform participants of the purpose and nature of my observations and gain their informed consent, particularly from older stroke patients. During the first periods of observations I introduced myself and explained my purpose to participants in a simple and straightforward way and ensured that they consent to my presence in the setting. When talking to older patients, sometimes I needed to offer repeated explanation within a single period of observation.

Another important consideration were the difficulties involved in attempting to gain and maintain consent from everybody who was likely to enter the field during a period of observation (Mulhalla, 2003). I tried to ensure that I always introduced myself and the study to other people such as professionals, patients and carers who were not recruited into the present study as participants but were in the unit at the time and check that they were also happy about my presence.

Ethical principles require that the research does not cause harm to participants. However, during observation in an acute care setting, the researcher may encounter a situation in which they may observe inappropriate practice. This poses a difficult ethical challenge about what appropriate action needs to be taken if these situations happen (Watson and Whyte, 2010). I decided that I would intervene if safety was compromised (e.g. being at risk of physical injury) or if the patient was experiencing serious emotional distress. However, despite my initial concerns during field work my presence was readily accepted by participants, who wanted to share with me their decision-making experiences during informal interviews. As will become clear the use of observation generated rich data.

The Qualitative Study Process and its Application in the Present Study

The following sections provide a detailed discussion and explanation of how the GT methodology was applied in the present study and considers the sampling technique used, data collection procedures and analysis methods, beginning with a consideration of the setting.

<div align="center">The setting</div>

The hospital in which the study was undertaken was selected on both theoretical and pragmatic grounds. From a theoretical point of view, my main intention was to uncover a variety of different perspectives and develop a theory which accounted for a range of decisions taken within the context of acute stroke. The hospital within which the study took place has already been considered in the background chapter. As was noted there this particular hospital was chosen due to the high probability of gaining access to a well-established and well regarded acute care context that served differing populations and gave access to a wide variety of potential informants. Both the setting and people within the environment were likely to provide rich data and offer meaningful insights into the topic under study.

Second, the selection of the study site was based on pragmatic reasons such as geographical location and the relationship between hospital manager and the researcher. It was geographically close to where I live, facilitating easy access for data collection. I had also previously met and collaborated with the Hospital Director in the context of another unrelated study and he had expressed willingness to participate in further research projects.

As described previously, the hospital concerned was a general hospital affiliated with a medical university located in Tianjin, one of the four municipalities directly under the administration of the central government in China. It has 1100 beds and 35 clinical departments, such as medicine, surgery, gynaecology and obstetrics, paediatrics and TCM. The participants in the proposed study, i.e. older patients with stroke, their family members, and health professionals were recruited from the wards at the neurological department of this acute hospital.

The participants

In selecting participants I used a combination of purposive and theoretical sampling, with a purposive sampling strategy being used in the initial stages of the study, after which ongoing theoretical sampling was employed. Purposive sampling was initially used to select subjects who represent the target population in respect of their role, unique knowledge or expertise about the phenomenon or insights into the context, position or relationship with other people in the setting and willingness to share their stories (Berg, 2007).

In the current study, participants comprised older patients with stroke who were selected based on the following main criteria:

- Medical diagnosis of stroke;
- Aged 60 years of age and over;
- A 2-3 week duration of stay in the hospital;
- Being able to give informed consent;
- Being able to participate verbally in the interview;
- Being considered medically stable by physicians;
- Participation in the study was not seen as a heavy burden for the patient.

Exclusion criteria were:

- Having severe multiple-morbidity (somatic, psychiatric and/or psychogeriatric);
- Having severe speaking and/or hearing problems or disturbances;
- Having cognitive impairment.

In terms of sample selection for family carers and health professionals, I decided to adopt as few additional criteria as possible in order to engage a wide variety of participants and incorporate varying voices and diverse perspectives into the research. Accordingly, the stroke patients' family members who had been informed about the study and agreed to take part in the study were also recruited if they:

- Were aged over 18 years old;
- Identified themselves as a family carer of a patient with stroke in the current hospital;
- Were personally involved in the process of admission, hospitalisation, or discharge.

The sample comprised a mixture of spouses, adult children and significant others. As family members normally stayed on the ward throughout most of the day, this provided numerous opportunities to include them in the study.

The health professionals (nurses, doctors, physiotherapists, acupuncturist) working in the current ward were invited to participate in the study. I tried to access a wide range of participants to capture the full range of variation that existed in a given phenomenon (Rodwell, 1998). For example, I recruited physicians from all four different medical teams.

Once access was granted by the administrator, participants who fulfilled the above criteria and might be interested in taking part in this study were identified by the director of the neurological department, who either gave the information sheet to potential participants or arranged for a colleague to do so. This strategy was commonly used when I recruited all three types of participant groups, i.e. health professionals, older patients with stroke and their family carers.

If the potential participants were interested in the study, they asked the director (or colleague) to give their names to me. I then approached them individually and provided detailed information about the purpose and procedure of the study and the voluntary nature of the participation to every potential participant. Some older stroke patients wanted their families to be present when I explained the study to them and in these instances patients and families jointly agreed to participate in the study. Consent forms were signed by those individuals who agreed to participate in the study and then an appointment was made for the initial interview to be conducted. The nature of any potential observation was carefully explained.

Theoretical sampling

As noted above, theoretical sampling is a fundamental principle of GT methodology (Glaser, 1998) and I employed theoretical sampling so that subsequent data collection was guided by the preliminary analysis. Sampling decisions were made throughout the concurrent data collection and constant comparative analysis process. For example, initial data analysis showed that patients'/carers' economic or financial condition was an important factor influencing decision-making. When patients/carers had financial difficulties, especially when patients did not have health insurance and had to pay the costs by

using their own money, patients/carers were more likely to refuse the examinations or treatments, in particular if a high cost was involved. Sometimes they might even refuse an examination due to the high cost of the subsequent treatment which was not covered by health insurance. However, a good financial condition could allow them to accept examination or treatment without being concerned about the cost. These initial data were collected mainly from professionals and patients/carers who had a good economic condition or had health insurance. Therefore, in order to explore the influence of a poor economic condition on decision-making, patients/carers who came from poor backgrounds, did not have enough money, or did not have health insurance to cover their health care expenses, such as people from rural or farming area, farmers living in the country, or laid off workers, were subsequently recruited. More details regarding theoretical sampling is provided later. Theoretical sampling helps to ensure that the researcher explores a variety of different perspectives thus making it more likely that he/she will develop a theory which accounts for behavioural variation (O'Donoghue, 2007; Charmaz, 2006; Taylor and Bogdan, 1984).

Theoretical sampling also applied to observations. Therefore, because all the observations were carried out during the daytime during the first round of data collection during phase two I spent time during the evening and night observing how people made decisions.

Socio-demographic characteristics of participants

The socio-demographic characteristics of the older patients with stroke, their family carers and health care professionals are summarised in Appendix 13-15. A total of 19, 27, and 25 interviews were undertaken involving 19 older patients with stroke, 28 family members, and 25 professionals respectively.

Nineteen patients who met the inclusion criteria were selected, with 14 male and 5 female patients. Their ages ranged from 60 to 80 years. The relationships of the 28 main family carers to older people with stroke ranged from sons (7), daughters (12), husbands (3), wives (5), to son-in-law (1), with the majority (17) being female and the remaining carers (11) being male. The ages of family carers ranged from 33 to 77 years.

Among 25 health care professionals, there were 15 doctors, 7 nurses, 2 physiotherapists and 1 acupuncturist. Nineteen participants were female and 6 were

male. Their ages ranged from 24 to 46 years and their years of clinical experience (in particular their experiences of working with older people with stroke and their families in a clinical setting) ranged from 1 to 20 years.

Data collection procedures

Data collection for the study was conducted in two phases over an 8-month period. Phase one consisted of data collection from a purposive sample of older patients with stroke, family carers, and professionals in the neurological wards of an acute care hospital. Semi-structured interviews and participant observation were used to explore their perceptions and experiences of making decisions. Co-construction of the findings with professional participants by email communication was also carried out at this stage (see later for a detailed discussion). Preliminary findings from an initial analysis of the data from this phase guided the theoretical sampling of participants and phenomena or situations in phase two.

Phase two of data collection involved theoretical sampling, e.g. recruiting uninsured patients and/or carers for interviews, undertaking observations in the evening and at night, elaborating on key themes or further exploring important topics or issues, as well as member checking with previous and new participants. A more detailed description of these processes now follows.

Phase one data collection

Methods of data collection used at this stage included face-to-face semi-structured interviews with older patients with stroke, their family members, nurses, physicians, physiotherapist, and acupuncturist, together with participant observation during stroke patients' 2-3 week hospital stay.

Participants recruited at this stage included 20 health professionals (11 doctors, 7 nurses, 1 acupuncturist, and 1 physiotherapist), 15 patients (13 men and 2 women), and 18 carers (6 sons, 7 daughters, 2 husbands, 2 wives, and 1 son-in-law). I completed 20 interviews with staff, 12 with patients, 14 with carers, and 3 with both patients and their carers at their request (Table 4.1).

I also carried out observations from 8:30 am to 5 pm for 55 days in total, with about two weeks focusing on each of the 4 different medical teams respectively. The overall phase one data collection lasted approximately five months and was carried

out from July to November 2010.

**Table 4.1 Numbers of Participants Recruited and
Interviews Undertaken During Phase 1 of the Study**

	Number of participants	**Number of interviews**
Patients (15)	Male 13 Female 2	12 interviews with patients
Carers (18)	Son 6 Daughter 7 Husband 2 Wife 2 Son-in-law 1	14 interviews with carers 3 interviews with both patients and carers
Professionals (20)	Doctor 11 Nurse 7 Acupuncturist 1 Physiotherapist 1	20 interviews

- Semi-structured interviews

Open-ended semi-structured interviews should be employed when the researcher knows relatively little about the subject area (Charmaz, 2006). An open-ended interview schedule for patients, families, and health care professionals was developed and prepared based on the study aim and objectives and with reference to the sensitising concepts and the foreshadowed questions. The topics covered and the clarity of the questions listed in the schedule were also discussed with my supervisors. The interview schedule was then translated into Chinese and included questions on the socio-demographic characteristics of the participants. A list of open-ended broad topic areas such as, 'In your opinion, what is (patient or carer participation in) decision-making?', 'Who is usually involved in decision-making?', 'How do you make decisions?', and 'What are your experiences of making decisions with patients and their family carers?' were finalised (see Appendix 16-17 for an interview schedule).

Without using a specific set of questions that were asked in a specific order and worded in a given way, I used these general questions or topics to guide the interview in order to allow the participants to tell their stories in a narrative fashion, to encourage conversations without leading only to 'yes' or 'no' responses and to ensure that all areas of interest were covered in order to try and get as complete a picture of the participants' experiences as possible (Kvale, 1996).

One patient, one family carer, and one member of health care staff (i.e. physician) were recruited and interviewed prior to the main study in order to test the interview schedule, assess and confirm the feasibility of the semi-structured interview and appropriateness of the interview questions and refine interview questions. The interviews allowed the participants to talk about their experiences and perceptions regarding decision-making and were recorded and transcribed.

This pilot phase provided important insights into the data collection method. Participants felt that the interview questions were clear and easily understood and although the interview took around 40 minutes with the patient, 50 minutes with the carer and 80 minutes with the physician respectively, the participants did not feel that this was too long. The fact that the physician talked to me for 80 minutes during the initial interview was encouraging and enhanced my confidence in the potential of the study to collect the rich data through working with participants. This physician demonstrated a strong interest in the study as she not only spent a long time participating in the interview, but also communicated with me during my observations and was actively involved in the co-construction process at a later stage.

In addition, minor changes to the interview followed the pilot phase. For example, the original Chinese terms (e.g. '决策' or '决定') in the interview questions were revised to other terms (e.g. '选择' or '拿主意') as being more appropriate and easy-to-understand translations of the English term 'decision-making' . This adjustment made the interview questions more approachable and suitable for the participants, especially for patients and carers. Ongoing adjustment to the interview schedule occurred throughout the process of data collection.

Early in the interviews it was clear that patients and carers wanted to place their experience of stroke in the wider context of their health more generally. Therefore, I started the interview by asking them to describe their experiences of illness or health care to date leading up to the stroke. "Grand tour" questions such as these help participants to tell their story of an event, put them at ease and help them to relax and allow them to set the direction of the interview (Spradley, 1979, p. 90). The researcher is then able to follow the leads which the participants provide rather than dictating the content of the interview. I used probes to explore issues that did not arise spontaneously, but did so towards the end of the interview to ensure that topics seen as important by participants were considered first. I was also alert to when the participants started giving 'yes' or 'no' responses, which would not

provide much information for data analysis. 'Yes' or 'no' responses prompted me to probe further with questions such as, 'Please tell me more about…' This ensured that the information needed for further in-depth exploration was provided and that the interview was more fruitful (Berg, 2007).

o Conducting the interviews

The interviews were conducted at a time and place of the participant's choice. The interviews with patients were usually undertaken after they finished their treatment and those with carers when they were available and were not busy looking after their relative. The interviews with professionals were usually carried out after work. This allowed participants sufficient time to share their experiences and stories as fully as possible and concentrate on the discussion without being distracted by any other concerns or thoughts.

In most cases, the interviews took place in a quiet room located near the ward in the hospital with little chance of being disturbed and where privacy was provided for the participants to openly share their experiences and perceptions. When patients or carers preferred, the conversation was carried out with them at the patient's bedside on the ward, sometimes with the curtains drawn around their bed space so that the patient could stay in bed and still have some privacy.

The interviews lasted between 30 and 150 minutes, with the majority being approximately 40 minutes with patients, 50 minutes with carers, and 80 minutes with professionals. The interviews were recorded with the participants' permission and transcribed verbatim. Some patients/carers requested that they wished to discuss something with me but didn't want it to be recorded and so chose not to use a recorder, but would rather spend more time with me to allow me to take relatively more detailed notes during the interviews. The main reasons why some patients/carers disliked using a recorder included: simply feeling nervous about being recorded; being concerned about possible negative consequences for themselves and being unfamiliar with qualitative research and interviews as a data collection method. Using a recorder provided an opportunity to capture everything that was said, but note-taking during and after my interview was a good substitute. In order not to leave out important information I asked participants to speak slowly so as to enable me to write down their experiences. I followed my supervisor's suggestion and dictated additional notes into my recorder shortly after the interview, especially any information which was closely related to participants' decision-

making activities and experiences. This formed part of the preliminary analysis process.

To assist in the constructivist process, the interview schedule was presented to the participants before the interview started to allow them to take a look and have a preliminary understanding, or I briefly introduced the main topic areas to the participants when appropriate. Open-ended questions, such as: 'In your opinion, what is (patient or carer participation in) decision-making, what are your experiences of making decisions?' guided the interview. In order to follow the principle of constructivist interview, participants were encouraged to freely discuss things or raise topics which they considered to be most relevant and important from their own experiences. Throughout the interview I tried to ensure that we were jointly creating an understanding of the study phenomenon according to constructivist principles (Rodwell, 1998). First, I repeatedly rephrased what the participants said during our discussion to check my interpretation and reflected my understanding back to the participants. Second, if participants found it difficult to answer my questions or struggled to talk to me I also shared some of my own experiences with them, such as how I made health related decisions with my mother when she had a stroke.

These strategies not only provided a way of creating a 'joint' understanding with participants guided by constructivist principles, but also enabled the conversation to go smoothly and helped me establish a partnership with participants. Consequently, the interview was informal, relaxed and took the form of a conversation with me responding to and developing points raised by participants. The purpose was to put participants, in particular older patients and their family carers, at ease and allow them to talk freely about their experiences and describe their own views regarding decision-making as fully as possible.

According to Morse and Richards (2002), one of the strengths of open-ended interview as a data collection tool is that participants tend to tell stories in a temporal sequence. In the present study, the participants, particularly older patients and their family carers, shared their stories in a logical order that helped me clearly understand the sequence of events that happened and the decisions that were made throughout the patient journey.

As a part of the hermeneutic activities, the issues or themes that emerged during the early interviews and were found to be particularly important were also introduced

into subsequent interviews and raised with the participants, in particular during the second-phase data collection (Rodwell, 1998). Questions such as 'One of the things that some people have pointed out in earlier interviews is…' or 'One of the things I'm finding is….would you say that fits or reflects your own experience?' were used for this purpose.

However, careful attention was paid to the appropriate timing of asking these types of questions, and I tried to present to the participants these major ideas towards the end of the interview process and if they didn't mention them, rather than at the very beginning and then ask for their perspectives.

The quality of the research project depends greatly on the researcher's ability to acquire information (Morse and Richards, 2002). To try and ensure this I adopted a number of approaches. Firstly, I made a conscious effort to eliminate preconceived ideas about the phenomenon under study, and entered the field with a relatively open mind. For example, in the literature, the findings of some studies had highlighted the key role that families played in making health related decisions for their sick relatives, therefore, when interviewing patients, carers or professionals, I tried not to ask leading questions such as 'does the family carer usually make decisions?' or 'is the patient often willing to leave decisions up to families?'. However, I attempted to keep the question very open by asking, 'who usually makes decisions or who plays an active role in making decisions?'

Secondly, throughout the interactive interview, I tried to appropriately direct the interview for the purpose of keeping the participant on topic and minimising unrelated information. I listened attentively, enthusiastically and conscientiously, and followed the participant's description cautiously without interruption so as to keep track of the story (Charmaz, 2006). I periodically asked the participants to review, discuss and clarify information, and paid close attention to their responses (Steeves and Kahn, 1995).

Thirdly, when the participant described a broad perception or experience, I often asked them to think of and give a concrete example of something that had happened and to explain it to me in detail. And I then asked follow up questions to help them to tell me in detail about the situation or phenomenon. This proved a good way of enabling participants to open-up and share their stories with me, and a useful strategy for improving and enhancing my own understanding of the key messages which the participants were conveying to me.

Towards the end of the interview, I summarised the main ideas that had emerged and checked out my interpretations and understanding with the participant. I also asked participants whether there was anything else which they thought I should know to better understand their decision-making experiences or whether there was anything important that they would like to share and add. These final questions proved very useful, as the participants' answers were fruitful and often produced additional important insights into the research question as well as areas which were worth further exploring during the subsequent interviews.

The interview was usually terminated when no new information was forthcoming. However, sometimes when older patients or carers became tired or distressed, or when some visitors interrupted our conversation, they suggested stopping the interview before all topics were covered, then the interview was also terminated and another opportunity was sought to address outstanding issues (Rodwell, 1998).

Immediate support was also provided to the few participants who became distressed, or experienced strong positive feelings and emotions (Long and Johnson, 2007). For example, one wife became immediately upset and anxious when she talked about her husband's severe condition and the tiredness and exhaustion that resulted from caring for the patient for a long time; and one nurse burst into tears when she recalled how happy they were when the carers appreciated the nurses' efforts in helping them to decide to accept doctors' treatment advice and successfully save the patient's life. Under these circumstances, I tried to comfort them by either holding their hands or patting them on their shoulders. Neither of these participants wanted to stop the interview.

At the end of the interview, I informed participants if they were happy to take part in a further discussion in the future either face to face, via the telephone, or by email as appropriate. This served several main purposes: to comment on the summary of their discussion: to ask older patients and their carers whether they had any new experiences of making decisions after the patients had been discharged back home; to carry out member checking and ask participants for their feedback on the major findings.

o Writing field-notes about the interviews

Field-notes are written descriptive explanations in which the qualitative researcher documents what is taking place in the setting, and the events that the researcher hears, sees, experiences and thinks about during the process of collecting or conceptualising data. In-depth, precise and broad field-notes are central to successful qualitative study (Bogdan and Biklen, 1982).

As a data collection technique, field-notes are often employed to complement interviews and to place interview data within a context such as the setting, the feelings the interviewer gained, and the non-verbal communication during the interaction with the interviewee (Rodgers and Cowles, 1993).

In the current study, field notes (Appendix 18) were collected immediately following each interview. The main purpose was to track important information and so facilitate interpretation of the data, which included the date and time of the interview, as well as the non-verbal communication of the participant, the feelings expressed, the context of the interview, the characteristics of the interview venue, any significant events, together with my thoughts, ideas and impressions regarding the interview and the participant.

• Participant observation

Although she proposes that the interview is the primary method of data collection in constructivist research, Rodwell (1998) also emphasises the important role of observation in complementing and supporting the information gained from interviews. Therefore I felt that using observation in addition to interviews with participants would be beneficial to gaining an in-depth and comprehensive understanding of the research topic.

Gold (1958) described four 'master' roles for the researcher when conducting observation in field work, namely complete participant, participant as observer, observer as participant, and complete observer. One important factor determining the degree of researcher's participation in observational study is the nature of the setting. According to Gold (1958), there are important differences between the observer roles available to a researcher. The two extremes are the complete participant role, in which the researcher's real identity and purposes are not made known to research participants, and the complete observer role, in which the

researcher observes from outside the setting and is not visible to participants who therefore do not know the researcher is observing them (e.g. using a hidden video camera or a one-way mirror).

In between are the 'participant as observer' role, where the researcher's purposes are known by participants, and both parties are aware of their relationship in the field work, but the researcher participates fully in ongoing activities of the research setting, and the 'observer as participant' role, in which the researcher reveals his or her purpose, formally observes within the setting but the extent to which the researcher actively engages with the participants is limited (Gold, 1958).

The two 'extreme' roles raise a number of ethical issues and were not considered appropriate for use in this study. Since the current study was conducted in the neurological wards of an acute care hospital, it was considered more appropriate and feasible for me to take on the role of an observer as participant in order to further understand people's actions, interactions and exchanges, rather than play a role of participant as observer and fully participate in their work or daily activities as a member of staff within the setting. This role has been commonly used by many researchers in a variety of hospital and nursing contexts (Casey, 2006).

According to Rodwell (1998), participant observation within a constructivist inquiry should be an interactive process during which there is ongoing dialogue and feedback between the researcher and participants. As an observer as participant, I carried out periods of observation on the ward of the neurological department, and observed, with the participants' permission, processes or events in which decisions might be made. The main purposes of my observation were:

- To better understand how decisions were actually made and to what extent professionals informed the family and patient and involved them in decision-making in everyday health care encounters;

- To complement interview data by exploring in greater detail the range of factors within the setting or context which either facilitated or inhibited patients'/carers' decision-making activities;

- To try and capture the whole picture and enhance the understanding of the total experience of patients'/carers' decision-making process;

- To explore the similarities and differences between the interview data and observation data;

- To use observation to inform subsequent interviews. For example, I used observational data to raise questions when I interviewed participants, such as why a patient insisted on early discharge, or how a son made the decision about thrombolytic treatment for his mother. I asked my interview participants how these decisions were made and how they felt about these experiences.

The observations mainly took place during the day, and involved me accompanying various members of staff (e.g. doctors, nurses, or physiotherapists) when they interacted with the patient or family (e.g. explaining treatment plan, talking to carers and requiring them to make decision on treatment for their patient, giving IV infusion, or giving physical therapy), and when they communicated with each other with regards to important decisions regarding patient care.

In order to capture the full range of variation in the events or phenomena happening within the hospital setting, I carried out observation of decision-making behaviours with each of the four medical teams (Rodwell, 1998). This was important as there were four different medical teams in the neurological department responsible for their own particular group of patients and they carried out daily ward rounds independently and separately. When I observed this particular event, I attended ward rounds held by each medical team on a block of consecutive days with each block lasting three or four days. Meanwhile, I constantly worked with and maintained contact with the same team of physicians over the same period of time.

My field work also included attending ward rounds, patient education sessions, discharge discussions (due to the lack of formal discharge plan meeting), or team meetings, following participants around, hanging around on the ward, and sitting in the ward or staff's office. During the process of observation, I mainly looked at processes or events where decisions might be made, and closely observed both verbal communication between participants and their non-verbal behaviours or body language as recommended by Efraimsson et al. (2004).

I stayed on the ward from 8:30 am to 5 pm, and spent about 8 hours doing observation during the day. I carried out 55 days of observation, during which, I spent 13, 14, 13, and 15 days working alongside each of the four different medical teams respectively. By acting in this way I tried to ensure the prolonged

engagement and contact with participants to gain an in-depth and comprehensive understanding of their experiences of decision-making with patients and carers, and to build trust and rapport with participants.

According to the principle of theoretical sampling, preliminary analysis of the observational data guided the sampling or selection of the incidents to observe next. For example, it was observed that one doctor who demonstrated a paternalistic attitude towards patients and carers during the interview seemed to have less patience when explaining treatment to them during the ward round. Therefore, I deliberately observed the ward round carried out by the doctor who explicitly welcomed a partnership working style in order to discover how he gave treatment related information to patients and carers and identify the potential differences between the two doctors.

While observing decision-making practice, I was aware that my presence might affect participants' decision-making behaviours. In order to reduce this possibility I adopted a number of strategies, for example:

- I explained to the participants that my role was a 'student' doing research and I was in no way 'monitoring' their performance (Fox, 1998; Stoddart, 1986);

- I achieved prolonged engagement in the field by spending a long time establishing trust and rapport with participants (Turnock and Gibson, 2001);

- I tried to position myself as unobtrusively as possible during observational periods, e.g. sitting in a corner of the doctor's office when observing doctors' work, trailing along and standing at the back and trying to be as unnoticeable as possible when observing doctors' ward round and their interaction with patients and carers (Fox, 1998; Stoddart, 1986).

The reaction of those I was observing suggested that these strategies had been successful. For example, after spending a couple of days doing field work, several staff members began describing to me something about their personal feelings about their job such as getting exhausted due to heavy work load and lack of staff, or sharing with me their own working experiences such as difficulties encountered or frustrations created when failing to advise the patient to make an appropriate decision.

Many staff members demonstrated a long term and on-going interest in my research throughout the whole study process, for example: proactively offering me information regarding a possible incident for observation, e.g. when and where the doctor would have a discussion with the carer about the treatment plan, or when and where they would hold a health education session for patients and carers; or sometimes telling me what happened when I was absent, e.g. how a decision was finally made by a certain carer for the patient.

Patients and carers also seemed happy about my presence and knew my role as that of a research student. They also were willing to talk to me and often took the initiative to share some of their experiences such as the patients' treatment effects or progress.

Participants' reactions suggested that they had accepted me and felt comfortable in my presence in the setting and this gave me some confidence that usual behaviours had not been unduly affected by my presence. This was further reinforced by the fact that I observed what might be thought of as 'inappropriate' behaviours, such as some professionals' impatient attitudes towards patients and carers, as well as some carers' poor behaviours like abruptly interrupting the patient when he or she was talking to the doctor or totally ignoring patient's desire to participate in decision-making.

As with the interviews I supplemented my observations with field notes.

- o Making field-notes during observation

Note-taking is essential but can be a challenging task in observational research due to the richness of the phenomena and the setting (Spradley, 1980). During an observational session, I only made brief hand-written notes either at the time or immediately afterwards. Sometimes, I dictated additional notes into a recorder shortly after the observation if I needed to save time and not to lose important information. However, when I finished a period of field work and was back home, I made a more detailed account of my observations (see Appendix 19 for an example of my field notes).

Patton (2002) points out that in carrying out observational inquiry, field-notes do not necessarily comprise just a record of what happened while the researcher was observing, they may also include the account gained from other types of

information sources, such as interview data. Informal conversations were carried out with patients, families, and health professionals if opportunities arose and field notes were used to record the main issues discussed, key messages delivered, or explanations that they gave about events or particular issues.

- Using other types of data sources

Aside from the large volumes of data generated from interviews and observations, information from other types of data sources can also be collected to facilitate the construction of meanings, improve the richness of data and analysis, or test and validate ideas or understandings (Rodwell, 1998).

During my field work, documents, which are defined by Rodwell (1998) as "nonhuman data sources" (p. 69) were included into the construction to provide background information to better understand the context of the setting. To achieve this I negotiated access to relevant written documents, including a wide range of materials, such as:

- o Patient treatment and care plans,
- o Patient progress records,
- o Flow chart on procedures of admission and discharge,
- o Health education information or posters on the wall or the notice board,
- o Written regulations on health insurance policy,
- o Different types of forms, e.g. consent form for receiving treatment which is not covered by health insurance or for receiving treatment involving risks, or proxy designation form.

These documents were examined and read, and brief notes were made during each period of field work, and then a more detailed interpretation was undertaken afterwards (Patton, 2002; Spradley, 1980).

Phase two data collection

After the phase one data collection and preliminary data analysis, I went back to the research setting to conduct a second-phase of data collection. The main purposes of this were to:

- Carry out theoretical sampling based on the preliminary findings in order to collect data to test or verify the emerging theory (e.g. recruiting uninsured patients and/or carers for interviews to explore how the issue of cost influenced their health care decisions);

- Conduct observations in the evening and at night to gain a more complete picture of participants' decision-making experience;

- Elaborate on key themes or further explore important topics or issues (e.g. further exploring professionals' seeking behaviour (see subsequent chapters));

- To undertake further co-construction with previous and new participants to evaluate the quality of the study.

The same data collection methods were employed and data were collected over a three-month period between September to November 2011. Four patients (3 women and 1 man) and 10 carers (1 husband, 3 wives, 5 daughters, and 1 son) were recruited and interviewed, either separately or together. Five staff (3 female doctors, 1 male doctor in the department of digestive diseases, and 1 physiotherapist) also participated in the interviews (Table 4.2). Observation between 5 pm and 8: 30 am the next day during the evening and night time was carried out seven times.

Table 4.2 Numbers of Participants Recruited and
Interviews Undertaken During Phase 2 of the Study

	Number of participants	**Number of interviews**
Patients (4)	Male 1 Female 3	2 interviews with patients
Carers (10)	Son 1 Daughter 5 Husband 1 Wife 3	8 interviews with carers 2 interviews with both patients and carers
Professionals (5)	Doctor 4 Physiotherapist 1	5 interviews

- Theoretical sampling

As noted above the sampling of both participants and events were informed by prior analysis of phase one data, consistent with the principles of theoretical sampling. Some examples are provided below:

o In order to explore the influence of poor economic conditions on decision- making, I recruited patients or carers who came from a poor background, and who did not have enough or extra money or health insurance to cover their health care expenses. These were people from rural or farming areas or laid off workers.

o The initial data indicated that more highly educated patients or carers were more likely to actively make decisions, seek information from different sources, and use job skills. Therefore, I interviewed people with less formal education from rural or farming areas in order to look at what kinds of role they played in decision-making, whether they played a more passive role, lacked confidence to make decisions, how they sought information, and what kinds of skills they used.

o Some professionals in phase one reported that the oldest son was more likely to make decisions for the patient if the patient was from rural areas. Patients and carers from rural areas were then recruited and issues about family members' role in decision-making were further explored.

o In terms of gender differences in decision-making, male patients or carers were found to use their job skills when making decisions. In order to look at the influence of female patients' or carers' profession, I recruited more female participants to explore whether and how they used or drew on their job skills when making decisions and how their professions might have an impact on their decision-making process.

o In an earlier interview, a physician reported that in Southern China, older patients' brothers or sisters seemed to pay health care costs and make decisions for patients, but in Northern China, older patients' children might pay the costs and make decisions. However, this information only seemed to be of an anecdotal nature. Therefore, it was necessary to try and recruit patients/carers who were from other regions of China to explore how they made decisions and to understand the cultural difference of decision-making style at a regional level.

In addition to theoretically sampling as illustrated above, I also used the second period of data collection to further elaborate upon major themes emerging from phase one. This allowed me to expand understanding of the nature of several key

processes such as 'seeking', 'hiding' and 'tailoring' (see findings chapters), when these occurred and how they influenced decision-making.

As in the first phase, interviews were complemented by a period of observation. During the second phase of data collection I mainly spent time in the evening and at night being with older patients, their families and health professionals and observing their decision-making behaviours. Such observations were helpful in allowing me to obtain as complete a picture as possible of the full range of activities. Whilst major decisions were rarely made during these periods (unless an emergency arose), more mundane decisions between patients and carers did occur, such as decisions about how best to meet food preferences or how to deal with sleep problems.

As noted earlier in a GT study, sampling and data collection should continue until data saturation is reached, which refers to a point at which no new information about the participants' experiences can be discovered or identified (Glaser and Strauss, 1967). In the present study, data analysis indicated that the final three interviews in each group of participants yielded few new insights into the understanding of their decision-making behaviours, and so at this stage, it was appropriate to complete data collection. A total of 72 participants (19 patients, 28 carers, and 25 health professionals) had provided extremely rich and extensive data during the interviews complemented by over 60 days of observation.

Data analysis methods

The aims of a qualitative data analysis are to organise, provide structure to, and achieve some order from a mass of seemingly 'chaotic' data, and more importantly, to make sense of and elicit meanings from often huge amounts of information so that the data can be understood from the participants' perspectives or points of view (Nolan, 2008). As Nolan (2008) points out, analysis in qualitative research comprises a set of different techniques and approaches, and there is no one "correct" (p. 341) way to carry out qualitative analysis. The choice of method needs to be made depending on the different purposes of the study and the researchers' different theoretical orientations.

According to Schwandt (1997), qualitative data analysis refers to:

> *"The activity of making sense of, interpreting or theorising about data. It is both an art and a science, and is undertaken by means of a variety of procedures that facilitate working back and forth between data and ideas. It involves the processes of organising, reducing and describing the data, drawing conclusions or interpretations from the data, and warranting these interpretations. If data could speak for themselves, analysis would not be necessary."*
> (Schwandt, 1997, p. 4)

In the present constructivist GT study, data were analysed using the constant comparative method, central to GT Charmaz (2006). As noted earlier in this approach each piece of data is compared with every other piece of relevant data, and concepts or ideas emerging from the data are also compared with each other. Through this inductive method, the analyst remains close to the data at every early stage and progresses to a more abstract level through iterative and concurrent data collection and analysis, and therefore, more abstract concepts, theoretical propositions or theories are generated successively. However, as this was also a constructivist study I wanted to involve participants in the data analysis, if they wished to be and as far as was possible.

Analysis of interview data

Within a constructivist GT study, data analysis is essentially ongoing and continuously proceeds in parallel with data collection from the first exploration into the field (Charmaz, 2006). As advocated by Erlandson et al. (1993, p. 85):

> *"In the collection and analysis of data, it is sometimes hard to distinguish between when the collecting ends and when the analysis begins, for gathering and analysis are complementary, ongoing, and often simultaneous processes".*

Preliminary data analysis was carried out prior to the more in-depth and formal data analysis and was performed concurrently with data collection before data preparation started. This helped inform the ongoing development of or adjustments to the interview topics and observation strategies and facilitated the data collection process (Erlandson et al., 1993).

- Data preparation

Data in qualitative analysis comprise mainly text which itself can take different forms such as written narratives which are generated from transcribed interviews, written accounts in field-notes, as well as reflections, thoughts, and ideas recorded by the researcher. From the sociological perspective, such texts about human thoughts and behaviours are considered as the accounts of experiences, and often consist of a large amount of material which need to be examined, analysed, interpreted and understood (Ryan and Barnard, 2000).

For example, a researcher may need to study and synthesise hundreds of pages of interviews, field notes, written documents, or other texts to explain what happened and what they might mean to generate a GT (Charmaz, 2006). Therefore, before analysis starts careful data preparation is generally needed, in which data are transformed into written text to help facilitate further analysis (Patton, 2002).

Prior to data analysis, the data were transcribed in Chinese from the recordings of the interview on to a computer to provide a written narrative text. In order to become familiar with the data, I listened carefully to the recording as soon as possible after the interview. This also helped me monitor my interview technique, especially in the early stages to try and avoid any leading questions or words that participants found difficult to understand. Subsequently, the recording was transcribed, typed and stored in a computer file.

The interview data were transcribed verbatim or word for word from the interview, and nothing was rephrased, altered, omitted or explicated. Expressions, such as laughter, crying and silence which implied the emotional part of the participants' experiences were also included in the transcript. Any changes in voice or tone, significant stops, gaps, prolonged pauses and inflections were noted as they might imply or indicate that the topic or the specific experience was important or emotionally charged (Kvale, 1996). The transcription was then examined against the recording for precision, and revised if necessary.

In order to ensure the accuracy of data analysis, a number of interview transcripts were translated into English by myself for data analysis under the instruction of my supervisors, including the first 3 interviews within each of the 3 groups of participants (patients, carers, and staff), and an additional 5 interviews with patients,

6 with carers, and 4 with staff.

The reason why I chose to translate and analyse the first three interviews in each participant group under the instruction of my supervisors was that in doing so I would be able to get their timely feedback and advice on my interview techniques at an early stage of data collection and improve my interview skills as early as possible, as well as receive an indication as to whether my analysis appeared appropriate.

The choice of additional interviews was mainly based on the richness and relevance of the data. I wanted to send to my supervisors the interviews that contained what appeared to be key ideas and processes. All other data analysis was undertaken in Chinese, but key sections were translated in order to be included in the final thesis. As I am fluent in both Chinese and English and the translations were not for the purposes of scale construction or a similar activity it was not considered necessary to have a double back translation carried out by another person. More importantly, as will be described later, I took care to check out meanings with participants themselves, who provided a better indication of whether my analysis had captured their feelings and experiences.

- Constant comparative analysis

Verbatim transcripts of the in-depth interviews were analysed using constant comparative analysis, the basis of which is to deeply and comprehensively understand the data from the participants' points of view (Charmaz, 2006). This comprises a number of stages, and whilst these have been variously described by differing authors I followed the scheme advocated by Charmaz (2006). This begins with coding.

  o Coding

Coding is the process of defining what the data are all about and according to Charmaz (2006):

> *"Coding means categorising segments of data with a short name that simultaneously summarises and accounts for each piece of data. Your codes show how you select, separate, and sort data to begin an analytic accounting of them…Coding is the pivotal link between*

collecting data and developing an emergent theory to explain these
data. Through coding, you define what is happening in the data and
begin to grapple with what it means"
(p. 43, 46).

In other words, coding mainly consists of assigning names to each piece of data and identifying all relevant concepts from the data. Different levels of coding were performed during the different stages of data analysis, and consisted of two main phases, initial coding and focused coding.

Initial coding started as soon as the first piece of data had been collected and involved naming each word, line, or segment of data and progressed from word-by-word coding, to line-by-line coding, and coding incident to incident. Since there were a huge amount of data to code, the majority of the interview transcripts in this study were coded line by line, and some segment by segment or incident by incident (see Appendix 20 for an example of preliminary codes in the selected translated transcripts of an interview with a son of a female patient).

During the initial stage of data analysis, descriptive labels or "in vivo" codes which refer to terms used by participants themselves (Charmaz, 2006, p. 55) were used as much as possible to identify the key concepts described by the participants within each section of transcript. Thus, I was as far as possible using the participants' own words to capture phenomena. This reduced the imposition of my own biases and enabled the emerging category and theory to fit the data (Morse and Richards, 2002).

Charmaz (2006) suggests that the researcher should try to look closely at actions in each piece of data, and use words which reflect action as the codes rather than code data with preexisting concepts or categories. This strategy helps the researcher begin the analysis from participants' perspectives and avoid making 'conceptual leaps beyond participants' meanings and actions and adopting existing theories' (Charmaz, 2006) with the risk of generating a theory that provides an outsider's view.

In the present study, gerunds, that is, words ending in 'ing' were used to indicate actions or processes and give a strong sense of action, change or movement over time (Glaser, 1978).

The initial coding was facilitated by my immersion in the data and helped me identify relevant concepts, and stimulated further reflection about these concepts within the data. To achieve this questions such as "What is this data a study of?", "What does the data suggest?", "From whose point of view?", and "What theoretical category does this specific datum indicate" (Charmaz, 2006, p. 47; Glaser, 1978, p. 57; Glaser and Strauss, 1967) were asked during the initial coding process. This was followed by "focused coding" (Charmaz, 2006, p. 46).

Focused coding refers to:

> *"a focused, selective phase that uses the most significant or frequent initial codes to sort, synthesise, integrate, and organise large amounts of data…you (the researcher) use focused coding to pinpoint and develop the most salient categories in large batches of data', and most importantly, theoretical integration begins with focused coding and proceeds through all the subsequent analytic steps"*
> (Charmaz, 2006, p. 46).

Following immersion in the data and initial open coding during which numerous preliminary ideas and thoughts began to emerge, I started to develop focused codes which were the most significant, useful, or frequently emerging initial codes in an analytic sense. A number of these emerged, such as: seeking medical help; using past experience; making treatment decisions and so on. The focused codes helped to capture key ideas in the participants' statements and through focused coding, I actively engaged with the data, constantly comparing my codes and data with each other and thereby refined codes and moved across and between interview data and observational data to make comparisons between participants' experiences, behaviours and interpretations. Focused coding is an iterative or recursive process rather than an entirely linear one, in which the grounded theorist can go back to any of the previous stages and continue the inquiry from there (Charmaz, 2006). The coding process allowed me to learn from the data and gain a deeper and better understanding of participants' experiences, facilitating concept formation and categorization.

The focused codes allowed me to begin developing conceptual categories that helped me to go beyond coding at a descriptive level to synthesise data and move to a higher level of abstraction (Charmaz, 2006). Through more detailed and in-depth

examination of concepts and further constant comparative analysis of data both within and across interviews and observations, concepts were tentatively gathered or clustered, and grouped into similar ideas or common themes or patterns according to commonality of meaning allowing me to build categories and further reduce data.

Subsequently, similarities and differences of the concepts within each category were identified in order to further dimensionalise the emerging categories, and concepts that appeared to deal with the same content were organised into subcategories. The data, codes and concepts within each category were reconsidered in order to generate category titles (see Appendix 21 for an illustration of development of the category 'seeking').

After establishing categories, I started to generate descriptive criteria or rationales regarding the allocation of data to certain categories. These initial propositional descriptions were helpful in beginning to develop theoretical ideas that could explain participants' decision-making experiences (Appendix 22). The process of categorisation continued throughout the study, through which I developed and finalised the categories and subcategories.

I scrutinised and evaluated these emerging categories by going back to all the relevant data identifying any differences within and between categories, and comparing the experiences or behaviours of different participants and different events or phenomena. For example, I became aware that some of the provisional categories were important but still thin or weak, or remained incomplete or unknown. At this point I realised that I needed to re-enter the field and go back to my participants to seek more data that focused on a particular category. The main purpose was to either saturate or further dimensionalise the category and ensure that it was grounded in the rich data.

Data analysis continued through constant comparison and theoretical sampling. When data collection and analysis generated nothing new, or when no new events, concepts or ideas could emerge and be put into the categories or could further bring about the discovery of a new dimension to the research question, the categories were regarded as fully saturated (Glaser and Strauss, 1967), and descriptive paragraphs or statements about the categories were written.

While the analysis process went on, patterns, links, connections or relationships within and between categories and subcategories were identified and further explored. Initial hypotheses were formulated to explain these links and relationships within the data. Constant comparison facilitated not only the development but also the testing of relationships and initial hypotheses to allow for theoretical explanations (Charmaz, 2006).

The finalised categories and subcategories provided an integrated interpretation and explanatory account to illustrate the main findings generated from the entire body of data (Charmaz, 2006). At this stage, the key concepts relating to older stroke patients' and family carers' decision-making processes were integrated into a theoretical framework which formed the basis of the GT.

The process of constant comparison and theoretical sampling is closely related to theoretical sensitivity (Strauss and Corbin, 1998), which is a personal quality of the grounded theorist that integrates interpersonal perceptiveness with conceptual thinking, and helps him or her to effectively analyse the data and develop the theory that is faithfully generated from the data and grounded in the reality of the social world (Glaser, 1978). Strauss and Corbin (1990) define theoretical sensitivity as the attribute or ability of the researcher to be aware of the subtleties of meaning contained within the data, what is important in the data, to understand the data, to have insights into the data, to give meaning to data, and to extract relevant materials from the data.

Theoretical sensitivity comes from previous experience relevant to the study area, and an understanding of extant work in the field. I kept myself theoretically sensitive through reflecting on my professional and personal experiences with decision-making with older people and their families within the context of stroke, being well-grounded in the literature on the subject area, and constantly interacting with the data. The use of memos is key to this process.

- o Memo writing

Memo writing is a central part of the analysis process and Glaser (1978) describes memo writing as the "core stage in the process of generating theory, the bedrock of theory generation" (p. 83). As soon as coding began, memos were used to capture emerging ideas, insights, thoughts and perceptions regarding the analytical procedures. I also tried to identify my own biases through the use of memos. Corbin

(1986) defines memos as the researcher's "written records of the analytic process" (p. 108), and these allowed me to keep track of and preserve ideas that might potentially be useful and important at a later stage of the study.

Two types of memos were kept throughout the study, operational and analytic (Glaser, 1978). Operational memos consisted of my notes of the steps that I took at each stage in conducting the research, including what and where to collect more data or ideas about the methods, such as using email communication with professionals to get the preliminary and final findings back to them as part of the co-construction process (see later and Appendix 23)

On the other hand, analytic memos recorded ideas for coding and categorisation of data, theoretical sampling, possible focus for future interviews or areas for follow up and further exploration, emerging categories, links and relationships between categories, identification of core categories, and the reflections on these issues which came out from different stages of the study. I wrote similar analytic memos from my analysis of observation, and then compared the two sets. These memos became more detailed as the analysis proceeded and the study progressed (see Appendix 24).

Analysis of observational data

Field notes and my recordings of observations and perceptions were developed, revisited and refined following each period of observation through an iterative process. According to Rodwell (1998), in constructivist inquiry, the data from observations are generally not entered into the raw data that will be coded and categorised for analysis as is the case with the interview data. Rather they will be used as 'background' to increase depth and scope in the process of generating findings and developing interpretations and understandings. This approach was adopted in the current study. My main intention within the analysis was to look for themes, patterns or relationships that were related to practices or factors which either supported or inhibited older patients with stroke and their family carers in making decisions with health professionals in an acute hospital setting. Coding incident-by-incident is more appropriate for observational data than word-by-word or line-by-line coding partly because the field notes already comprise the researcher's own words and interpretations (Charmaz and Mitchell, 2001). In the present study, field notes were analysed through incident-by-incident coding or coding the whole events or scenarios.

From a GT perspective, analysis of observational data also involves constant comparison between multiple incidents, actions, experiences and participants (Charmaz, 2006), in which I compared incident with incident, compared new data with old data, and compared incidents with the understanding or interpretations gained from the analysis of earlier incidents and also of the interview data.

For example, I compared the same doctor's way of communicating with patients and carers during ward rounds on different days, compared different doctors' way of communicating with patients and carers during ward rounds, and compared the same doctor's way of communicating during a ward round with communication on other occasions, such as the discussion of a treatment plan with patients or carers in his or her office.

As mentioned previously, I wrote analytic memos during my observational field work. I compared the memos from my analysis of observational data with those regarding interview analysis in order to gain an integrated rather than a partial understanding of the findings generated from the entire data set, including the documents I obtained.

Information from a range of documents was used either to provide background information to better understand the context in which participants were acting, or as supporting data to increase scope and depth in the process of generating findings and developing interpretations. Documents as a more tangible form of data provided a useful lens into the decision-making practices of service users and providers in general, and studying these documents allowed me to put participants' decision-making behaviours, activities and situated routines into their larger social context of the unit and hospital as a whole (Østerlund, 2008). Documentary evidence played an important role in facilitating my understanding of the setting of acute stroke care, providing support for findings and interpretations regarding participants' perspectives of their decision-making experiences, and reinforcing the complexity of decision-making throughout the patient journey. For example:

- Examining patients' treatment and care plans and progress records helped me understand their decision-making needs at different stages of their journey;

- Flow charts on procedures of admission and discharge allowed me to understand the situated routine in the acute care setting and its impact on

patients' or carers' decision-making;

- Health education information presented on the wall or notice boards resonated with findings from interview data;

- Different types of consent forms were clear evidence illuminating how patients or carers exercised their autonomy through making informed choices on their own.

Co-construction of the findings

As the study adopted a constructivist approach I wanted as far as possible to engage the participants in the interpretation and analysis of the data. Much of this was relatively informal and either occurred as part of the interview process when I was careful to check out meanings as the interview progressed or as part of the observational period when I would take opportunities to chat to patients, carers and staff about their experiences and how they interpreted them. As patients were in hospital for only a relatively brief period and often came from quite some distance it did not prove possible to provide them with the opportunity to comment on and feed into the analysis process, other than as described above. However, I was able to take a more proactive approach with staff and decided to use email as a way of engaging with them, even whilst I was in the UK and they were in China.

Co-construction of the findings with health professionals by email communication was carried out after the 1st phase data collection and initial analysis were finished in order to involve the participants in generating findings during the data analysis process and ensure that the findings represented a shared construction (Charmaz, 2000).

I sent a summary of major findings across the data as well as the summary of key findings from their particular individual interview to them, asked for their feedback, and made alterations when necessary. Fifteen out of 20 staff responded to this invitation and gave me feedback on the preliminary findings through email communication (see Appendix 25 for an example of email communication).

Although the majority of the participants agreed with the preliminary findings, a few of them offered some useful and interesting input which elaborated upon the findings. For example,

- Carers who came from an extended family, and wanted to demonstrate filial piety were more likely to want their relative to die at home;

- Carers who were Buddhists or Muslims were more likely to refuse invasive interventions for their dying patient and prefer their patient to die at home;

- Doctors were more likely to disclose negative information or a poor prognosis to patients who had a higher education level or who held an optimistic attitude towards life and their disease;

Many participants responded positively to this process and thought that involving them in the research process reflected my trust in them and their capacity to contribute to the study.

Co-construction of the findings not only involved participants in data analysis, but also formed part of the member checking process in which data and analytic categories and interpretations were tested with participants in order to ensure that a good quality GT was produced (Lincoln and Guba, 1985). Detailed information regarding member checking is presented in Chapter 7 where I reflect on the strategies used for member checking and the extent to which the quality standards were met.

Drawing the data together

The use of three complementary methodologies of data-gathering enabled me to collect comprehensive information about the experiences and processes of decision-making. Once the analysis of interview, observational and documentary data was finished, the findings from different types of data set were integrated in order to produce a synthesis of findings from all data sources. This resulted in the development of a theoretical framework of decision-making of older patients, their family carers and professionals within the context of stroke. The results of the above processes are presented and elaborated in the following findings chapters. After evaluating the quality of the study, I held up the emerging theoretical framework against the literature to check for consistency and for any new information that might add to the knowledge in the area of decision-making within the context of stroke care. The result of this is illustrated in the discussion chapter.

Judging the Quality of the Study

Judging the rigour or quality of a qualitative study is a contested area, with many differing and sometimes conflicting frameworks being proposed. In judging the merits, or otherwise, of the present study I applied two sets of criteria. As the study had a constructivist philosophy at its heart I decided to use the main dimensions of the quality criteria for the GT as described by Charmaz (2006) (i.e. credibility, originality, resonance and usefulness), and the main dimensions of the authenticity criteria for the research process as originally proposed by Guba and Lincoln (1989) and endorsed by Rodwell (1998) (i.e. fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity). These are described in further detail below.

Quality criteria for GT

Charmaz (2006) suggests four fundamental criteria for judging or evaluating the quality of a GT and she describes these as: credibility, originality, resonance and usefulness (Charmaz, 2006). She elaborates these by outlining a series of questions that need to be asked by the resultant GT. This are reproduced below.

Credibility

- Has your research achieved intimate familiarity with the setting or topic?
- Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data.
- Have you made systematic comparisons between observations and between categories?
- Do the categories cover a wide range of empirical observations?
- Are there strong logical links between the gathered data and your argument and analysis?
- Has your research provided enough evidence for your claims to allow the reader to form an independent assessment – and agree with your claims?

Originality

- Are your categories fresh? Do they offer new insights?
- Does your analysis provide a new conceptual rendering of the data?
- What is the social and theoretical significance of this work?

- How does your GT challenge, extend, or refine current ideas, concepts, and practices?

Resonance

- Do the categories portray the fullness of the studied experience?
- Have you revealed both liminal and unstable taken-for-granted meanings?
- Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?
- Does your GT make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?

Usefulness

- Does your analysis offer interpretations that people can use in their everyday worlds?
- Do your analytic categories suggest any generic processes?
- If so, have you examined these generic processes for tacit implications?
- Can the analysis spark further research in other substantive areas?
- How does your work contribute to knowledge? How does it contribute to making a better world?

Source: Charmaz (2006, p. 182-183).

The above criteria attest to the quality of the GT itself, however of equal importance is the nature of the research process itself. For constructivist studies this can be gauged by using the 'authenticity criteria'.

Authenticity criteria

Guba and Lincoln (1989) suggest that quality criteria should reflect the underpinning philosophy of the research process and they developed the authenticity criteria based on constructivist assumptions about what constitutes an 'authentic' research process. These criteria comprise five elements: fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity. These are reproduced in the table below.

Table 4.3 Authenticity Criteria for Evaluating
Research within the Constructivist Paradigm

Fairness – the extent to which different constructions and their underlying value structures are solicited, obtained and inform the results. In other words, has everybody's voice been heard.
Ontological authenticity – the extent to which individual respondents' own emic constructions are improved, matured, expanded and elaborated. That is, do participants now have new insights into their own situation?
Educative authenticity – the extent to which individual respondents' understanding of and appreciation for the constructions of others outside their stakeholder group are enhanced. That is, do participants now better understand and appreciate the view of others?
Catalytic authenticity – the extent to which action is stimulated and facilitated by the (research) process. In other words, is there a catalyst for change as a result of the above insights?
Tactical authenticity – the degree to which stakeholders and participants are empowered to act. The ultimate test is therefore whether real change actually occurs.

Based upon Guba and Lincoln (1989) and Davies (2001).

These quality criteria were applied by Rodwell (1998) in a social work context and described as potentially the most radical dimension of constructivism. Authenticity involves the quality standards for an interactive and creative process that attempts to educate and empower individuals, and more importantly, through empowerment, to stimulate and facilitate actions which can lead to effective change (Rodwell, 1998). However, there is limited guidance regarding how the authenticity criteria might be achieved (Rodwell, 1998). They have also been the subject of some criticism due to the complex language that they use to define what are essentially relatively simple ideas.

As Nolan et al. (2003b) point out, if an underpinning assumption of constructivist inquiry is to enable all the stakeholders to be part of the process of producing knowledge (Lincoln, 2001), then the language and terminology used to convey ideas should be understandable to participants themselves. These authors did not feel that the authenticity criteria as described by Guba and Lincoln passed this important test. They therefore suggested a revision to the wording whilst keeping the underlying principles intact. This is outlined below and was adopted in this study.

Table 4.4 A Comparison of the Terms Used by Guba and Lincoln (1989) and Nolan et al. (2003b) in Relation to the Authenticity Criteria

Term used by Guba and Lincoln (1989)	Terms used by Nolan et al. (2003b)	Definition of term
Fairness	Equal access	All viewpoints are represented even-handedly
Ontological authenticity	Enhanced awareness of the position of self	Participants understand their situation in more informed ways as a result of participation in the research
Educative authenticity	Enhanced awareness of the position of others	Participants understand the situations of others in more informed ways as a result of participation in the research
Catalytic authenticity	Encouraging action by providing a rationale or impetus for change	Participants have a greater insight into actions that they might take to change their situation as a result of participation in the research
Tactical authenticity	Enabling action by providing the means to achieve change	Participants feel empowered and enabled to act as a result of participation in the research

Source: Brown Wilson and Clissett (2011, p. 679).

Summary

This chapter has justified the use of a constructivist GT approach in achieving understanding of the decision-making process between people with stroke, their family carers and professionals in an acute care context. The qualitative versus quantitative research debate, constructivism paradigm, indicators for selecting qualitative research, considerations informing the use of constructivist GT approach, important methodological issues and ethical considerations have been considered. The subsequent study design, sampling technique, data collection procedures and analysis methods and quality evaluation of the study have been detailed. A reflection on the use of constructivist GT method in this study is provided in Chapter 7. The next chapters present the results of the study.

CHAPTER 5: FINDINGS PART ONE

MAJOR CONTEXTUAL AND BACKGROUND FACTORS SHAPING DECISION-MAKING

Introduction

The overall purpose of the study was to explore the processes through which older people with stroke, their family carers and health professionals make decisions in an acute care context in China. More specifically, the objectives were to understand participants' perceptions and experiences of making decisions, examine factors influencing decision-making, identify types of decisions being made, and uncover the types of knowledge that informed decisions.

This, and the following chapter, will present the main findings based on the numerous interviews and periods of observation described in the preceding chapter. This chapter focuses on the major contextual and background factors shaping decision-making, while the next chapter mainly considers the core categories and how they interact to influence the decision-making process.

In presenting the data I have selected the quotes that best capture the dimensions of a category or sub-category, whilst also including as many participant voices as possible, in keeping with the tenets of grounded theory (Charmaz, 2006).

As noted above, this chapter focuses on the major contextual and background factors that shaped decision-making within the 2-3 week period of hospitalisation. The findings indicated that during this time patients, carers and staff were involved in making many, often complex, decisions that varied over time. Some decisions were led primarily by professionals, others by family members and others involved discussion between professionals, families and older people. In order to begin to appreciate the complex processes involved the following sections will consider:

- How older people, family carers, health professionals and other people were involved in decision-making;

- The types of decisions made at different stages throughout the patient journey. This will include factors influencing: initial help seeking and the choice of hospital such as hospital reputation; environmental factors such as distance

between patient's home and hospital and quality of the physical environment; and medical/treatment related factors influencing health care decision-making during hospitalisation such as risk/cost, urgency of decision or patient's condition, treatment effect, and feasibility or pragmatic issues;

- The types of knowledge that were used to inform decision-making;

- The influence of patient/carer related factors such as level of education, personality, gender, profession, age of patient, the carer's ability to pay, carer's perceived competence to make decisions, understanding about disease, health insurance, and economic/financial condition, and professional related factors such as doctor's experience, perceived seniority of doctor, patients' and carers' first impressions of doctors and staff expertise or quality of service.

This broad range of factors 'set the scene' for decision-making and were influential in the overall processes. However, two considerations played a major role and these conclude the chapter and provide an introductory context for the next chapter that considers the 'core' categories and their interactions in detail. The two factors exerting a major influence on decision-making were:

- The role of culture, especially the traditional Chinese ideal of maintaining harmony. The influence of culture at a regional level, professional level, team culture, family level and personal level are also outlined.

- The influence of 'trust' and how it was developed and sustained within patient/family/staff interactions is described.

Before addressing the types of decisions that were made at different stages throughout the patient journey, attention is firstly turned to the people who were involved in making decisions.

Who was Involved in Making Decisions and Why?

The findings indicated that throughout the stroke journey, many types of decisions were made at differing stages including before admission, around admission, during the patient's hospital stay, pre-discharge, upon discharge, and after discharge. A wide range of people were inevitably involved in the decision-making process, including older patients, their family carers, health care staff, and other relevant

people.

Sometimes decisions were made either entirely independently or primarily by one individual, whilst at other times decisions were made collectively by a group of people through a participatory process. As will become clear a variety of factors meant that older people very rarely made major decisions independently and it seems appropriate to start with the factors shaping their involvement.

Patients usually made, or played a major role in decisions, if they: had normal consciousness level; usually made decisions within the family; had no children or their children were not available (e.g. in another city or abroad); used to be a health professional (e.g. doctor); were relatively young; had a higher educational level; or could control the distribution of their property or legacy. However, even in these circumstances many older people were effectively precluded from full involvement in decision-making by the desire of the family and professionals to keep potentially 'bad news' about their prognosis from them (see 'Hiding' in the next chapter).

It was therefore family carers who played the central role in decision-making in most situations, and they were often the main, and sometimes the only, people involved in key decisions, particularly in cases where the decision involved an element of risk or were costly (see later). Sometimes more than one family member was involved, especially in difficult circumstances that might involve the attribution of blame if things went wrong. As will be noted later, professionals were very happy for families to take the lead in such cases. In less contentious circumstances joint decisions involving all parties were possible. Family carers involved in decision-making included: the patients' spouse; children; children in law; brothers or sisters; or other relatives. Who was involved tended to vary dependent on the patient's age. For instance, husbands or wives often made decisions when the patient was relatively young. If on the other hand a couple lived with their children then it was usually the person who was the key family decision-maker who took the lead, this was often the oldest child. However, as will be seen this was not invariably the case.

Children-in-law were mainly involved as advice providers and usually left the final decision up to the patients' spouse or children. For example, the son-in-law of a female patient was involved in decision-making in different ways such as explaining the doctor's treatment plan to his father-in-law, who then made the decision. Sometimes the patient's brothers or sisters or other extended family

members were also involved. This seemed to have a regional variation and was more common in patients from Southern China or from a rural/farming background and reflected regional cultural variations (see later). For example, according to the wife of a male patient who was from a rural area, the key decision-maker was the patient's youngest brother who made the major decisions regarding the patient's health care and hospital treatment. This was because the wife was illiterate and the patient relied on his brother to make decisions in daily life as well. The quote below illustrates the extent of the reliance on the younger brother:

> *Carer20(2): "This time, when my husband was admitted to the hospital, I fully relied on my youngest brother-in-law to go through all the needed procedures, such as reading, filling out or signing different forms, and to make decisions for my husband. I said to him that since I couldn't read and write, so I needed to depend on him to do everything related to my husband's hospital treatment.*
>
> *I always have a discussion with my youngest brother-in-law rather than my husband whenever a decision regarding my husband's hospital treatment needs to be made. Actually my youngest brother-in-law makes all the decisions for my husband during his hospital treatment. For example, when my husband refused to be admitted to this hospital, all of us persuaded him to change his mind, of course, his youngest brother played a key role in successfully persuading him to accept the doctor's admission advice."*

The main role of health professionals in making major decisions that involved high risk or major costs was in terms of providing information or explanation to patients and carers, answering their questions and offering suggestions or advice. On the other hand, professionals (doctors, nurses, physiotherapists, or acupuncturists) made decisions about day-to-day routine investigations and then informed the family and patient.

Other people who potentially influenced decisions included: other patients and their carers sharing the same room or in the same ward; friends who were health professionals or had suffered from similar diseases such as stroke; neighbours who were health professionals or had suffered from stroke, as well as other members of the patient's social network (e.g. a male patient who was a breakfast seller followed his client's advice and deliberately stopped his anti-hypertension medications). The

main role of these other people was to act as a source of information that might influence the decision that was made.

Types of Decisions Made at Different Stages throughout Patient Journey

Older patients with stroke and their family carers made different types of decisions at various stages throughout the whole patient journey (see Appendix 26 for a full description). The text below gives an indication of the main types of decisions made at various stages and the factors that influenced these decisions.

Before admission

Patients' and carers' independent decision-making mainly occurred from the time of onset of the stroke symptoms up to admission to the acute care unit. For example, at the time of stroke, when patients or their carers identified a health problem or became aware of abnormal signs or symptoms, they needed to decide whether or not they were serious enough to seek expert advice. If they decided that they were, decisions about which hospital and/or doctor to choose were required. A number of factors were taken into consideration at this time, especially about which hospital or doctor to select.

At this point patients and carers were particularly influenced by the reputation of the hospital. If the hospital had a good reputation, either generally or amongst the patient's family group they were not only more likely to choose that hospital but also to trust the staff and follow their advice. They often chose such hospitals even if the accommodation offered was not ideal. This is illustrated in the quotes below:

> *Carer18(1): "We came to this hospital because the neurological department here is very famous in our city…and the staff in different departments collaborate with each other very well in this hospital."*

> *Carer26(3): "I think, we come to this hospital, our relative is admitted to your department, this is because your hospital has a very high quality service, and our relative can receive good examination and effective treatment."*

> *Patient10(2): "I called the staff in the current hospital to see if I could be admitted for hospital treatment, since I knew that this*

hospital was a very famous hospital with high reputation. The staff told me that they only had the extra inpatient bed which was placed in the corridor, and asked me whether I still would like to stay there for treatment. I said that I would stay at whatever place they could provide and I wouldn't like to find another hospital to go for treatment."

A range of environmental factors also played a key role such as the distance between the patient's home and the hospital, and the quality of the physical environment within the hospital. Not surprisingly, provided that they had a good reputation, patients and carers preferred hospitals that were located close to the patient's home.

Patient9(9): "Since this hospital is located close to our home, therefore we all would like to choose to come here to see a doctor and get treatment for our disease."

Patient4(1): "I directly came to this hospital for treatment, because I live very closely to this hospital and it's very convenient for me to come here from home."

If all other things such as reputation, proximity staffing levels were equal, attention was turned to the nature and quality of the physical environment. Hospitals that were known to be clean, orderly, quiet and comfortable were seen to be more conducive to recovery. However, as noted above 'reputation' was a pre-eminent consideration, even if this meant taking a bed located on the corridor.

The perceived urgency of the patient's condition also influenced the choice of hospital, so that if the situation was seen as life threatening then the nearest hospital was chosen, irrespective of reputation:

Patient5(2): "I was admitted to the current hospital since I had vomiting...I got dizziness and vomiting, oh, my God, I felt like I would die. Then I thought, I could do nothing about it, so I called my children, and then they took me to the current hospital to see a doctor in their car...since I live close to the current hospital, so at the time of stroke, I decided to come here to see a doctor."

Decisions made during the hospital stay

The most important and far reaching decisions, especially those relating to treatment, were made during the period of hospitalization itself, often within the first few hours or days. These included major decisions that were closely linked to the chances of a good recovery such as receiving examinations (e.g. MRI or MRA scan), treatments (e.g. thrombolytic treatment or surgical intervention such as percutaneous transluminal stenting), rehabilitation (e.g. physical therapy), acupuncture therapy, and nursing care (e.g. gastric tube placement, urinary catheterisation, or choosing hand for IV infusion). How such decisions were made will be considered in more detail later but they were influenced by a range of factors, especially the perceived degree of risk involved and any associated costs that would not be met by the patient's insurance.

At this point, decisions about the patient's other activities during their hospital stay (i.e. issues in relation to patients' diet, moving, or walking) played an essential role in facilitating improvements in activities of daily living and overall recovery. Such decisions complemented those relating to acute care interventions listed above.

The role played by family members who accompanied patients during their hospital stay and took responsibility for monitoring and reporting the patient's condition to professionals, as well as caring for the patient's daily needs was very important in ensuring a patient's good recovery. In order to reduce the burden of care on a particular individual, carers often shared the care within the family, with different members playing different roles. Important considerations at this time were who would give consent for various procedures (as will be noted later this was often not the patient) and who would pay any additional costs. This was not always simple. For example, although the oldest son of a female patient lived abroad, it was he who made the treatment decisions for his mother and then chose another family member to give consent on his behalf. Decisions made at this time had far reaching consequences for the family member involved. For example, when one patient suffered from paralysis after receiving percutaneous transluminal stenting, the main decision-maker had to take the patient back to his home and look after the patient because it was he who had consented to that particular surgical intervention and as the main decision-maker he was perceived as being fully responsible for the outcome.

During the patient's two or three week hospital stay, several medical/treatment related decisions were needed and a range of factors played a major role here including: risk/cost; urgency; likely treatment effect; and pragmatic issues.

Risk/cost often determined who was involved in decision-making and how decisions were made. In cases where neither risk nor cost was involved in treatment/examination, then doctors made the decision; if either risk or cost was involved, then patients or more often carers played a major role.

> *Doctor10(10): "The situation in which doctors don't need to involve patients/carers in decision-making is that some decisions on regular treatment/examination are needed to be made. But in some situations, for example, there are some treatments which have special side-effects or risks, or there are some invasive examinations, or there are some medications or examinations which are not covered by patients' health insurance, or which are very expensive, we will provide information to them (carers) and ask them to make decisions.*
>
> *For regular treatments/examinations, for example, the treatment which doesn't involve risk or cost, we will not involve them (patients and carers) in the decision- making process, but we may inform them about our decisions or just give them a general introduction about our treatment interventions."*
>
> *Doctor(13)3: "In certain circumstances, patients or carers need to make decisions based on information that we provide to them. First, they need to make decision on medications or treatments that they need to pay the cost on their own, that is to say, the cost is not covered by patients' health insurance. Second, when patients need to receive some treatments which involve risks, such as receiving thrombolytic treatment, receiving vasodilator therapy, receiving antibiotic skin testing for allergy, in these situation, carers need to make decisions, and decide whether to give their signed consent. And also when patients need to receive surgery, or when patients may have the risk of life-threatening situations during the transferring process between the ward and examination room, carers also need to make decision.*

On the other hand, when we will give patients some regular treatments/examinations, we will make the decision, and don't need to ask patients or carers to make the decision or seek their opinion or advice. We also let them know our decision or our treatment plan, such as which medication or which type of medication is giving to patient. That is to say, when the treatment or examination doesn't involve risk, the cost is covered by patients' health insurance, there is no need for patients or carers to make decisions."

The issue of risk was mentioned by staff and carers but seldom by older patients. As will become clear later this was because patients were often not told about risks and costs, especially risks, and were therefore effectively precluded from such decisions. When making decisions involving risks, such as whether to receive thrombolytic treatment which was associated with the risk of haemorrhage, carers were usually given information about potential benefits as well as complications by doctors, and asked to take both factors into consideration before making a choice.

Cost was also an important consideration. In situations where treatment, examinations or other health care interventions such as rehabilitation were very expensive and such costs were not covered by the patient's health insurance, or patients did not have health insurance and patients/carers were unable to meet such costs they were more likely to refuse the examination or treatment even though the patient had a strong clinical need for it. A physiotherapist said that:

Physiotherapist23(3): "Cost is one of the factors influencing decision-making, for example, if a certain examination or intervention is very expensive, or its cost is not covered by health insurance but has to be paid by patients or carers themselves, patients or carers will have a careful consideration before making decisions. Then if they don't think that the examination or intervention is necessary or important for patients, they will definitely refuse it since they can't afford its high cost."

Conversely, some doctors believed that free treatments were routinely accepted without consideration of the potential risks involved. However, this was not always the case as sometimes carers would refuse treatments that had no cost implication if the benefits were believed to be minimal. This issue of cost and perceived risks and

benefits was a delicate and sensitive one that could have potentially profound effects on treatment decisions, especially when decisions were needed urgently.

The urgency of decisions largely determined the time available. For example, doctors would set a time limit, and require patients/carers to make decisions as early as possible or within a certain period of time depending on the urgency of decision or the patient's condition. If it was a highly urgent decision, such as whether to give a patient a tracheotomy, carers were expected to reach a decision almost instantly. For treatments such as whether to administer thrombolytic treatment to a patient within the 4- to 6-hour time window, doctors would require carers to make decisions within a maximum of 30 minutes. This often put carers under considerable pressure. In such circumstances the perceived efficacy of the treatment relative to cost/risk was factored in. The more favourable the treatment effect was seen to be, the more likely patients/carers were to follow doctors' advice when making decisions.

Decisions about longer term treatment were more likely to be influenced by pragmatic considerations, such as the feasibility of returning for on-going out-patient treatment, as noted by the doctor below:

> *Doctor10(3): "Since some patients have difficulty walking and difficulty using arms to perform tasks or finish functions, so if they take Warfarin for prevention, there will be a problem, which means that they basically need to come to the hospital for a blood test at least once a week after they are discharged…since the patient has hemiplegia…it's very difficult for the family to bring him or her to the hospital again just for receiving a blood test. It would be difficult or highly inconvenient for family members to transfer the patient between hospital and their home, so this is an issue about the feasibility, whether it's feasible for a patient with hemiplegia to come to the hospital for a blood test after he or she takes Warfarin.*

> *For example, some carers don't mind the extra inconvenience that comes with bringing their patient to hospital for receiving a blood test, or they can draw the patient's blood at home and then bring it to the hospital for a test, so basically these carers will decide to give Warfarin to their patient. But some other carers may refuse the Warfarin treatment for their patient due to the difficulties involved in*

getting the patient to receive a blood test, and then select other methods."

Decision-making after discharge

Decisions around issues such as discharge and post-discharge recovery varied from one individual to another. Patients or their carers were usually involved in decisions regarding when to discharge. Most stroke patients stayed in the hospital for two to three weeks in order to receive adequate treatment and rehabilitation services.

Some of them might stay in the hospital for less than two weeks for one of three main reasons: because they could not afford the cost; they had lost trust in the hospital; or their recovery was quicker than anticipated and they were ready to go home. In the latter case, discussions about early discharge were usually initiated by the patient or carer and often depended on the doctor's judgement about the patients' condition. However, patients and carers could decide to discharge themselves irrespective of the doctor's advice. On the other hand, some patients had to spend longer than three weeks receiving in-patient treatment and rehabilitation simply because they couldn't fully recover within the regular LOS.

After hospitalisation, a number of decisions had to be made such as how to help the stroke survivor return to a normal life and daily routines as quickly and as fully as possible. Therefore, decisions about follow-up treatment at the OPD in the current hospital or receiving rehabilitation in a TCM hospital, choosing a doctor for follow up treatment, or deciding how to provide home care for stroke survivors, such as providing singing therapy, arranging sightseeing activities, managing gastric tubes, or caring for a patient with a tracheotomy were needed.

In an acute care hospital setting, family carers sometimes faced difficult decisions regarding death and dying, for example, whether they wanted the patients to die in the hospital or at home. This might involve decisions about whether to give up life-sustaining support to end the suffering of their terminally ill relative. As will be noted later, cultural factors sometimes exerted an influence here. For example, those with Hui nationality or special religious beliefs would refuse a tracheotomy because maintaining the 'whole body' of a dead person was more important to them.

In addition to the issues relevant to the patient's stroke, decisions might also need to be made about treatments for other pre-existing conditions, changes to life-style and

related factors. Since older patients with stroke often had multiple health issues, family members needed to manage other types of disease, for instance, patients with diabetes needed to make adjustments to their diet, take medications and give themselves insulin injections. Their ability to do so was often affected by the stroke.

It was clear from the data that carers were involved across the whole spectrum of decisions from what might be called strategic or major decisions (e.g. decisions in relation to examinations or treatment involving higher costs or more dangerous risks) to day-to-day or minor decisions (e.g. decisions about caring for the patient). The physical presence of a carer was not always necessary for them to exert considerable influence, as with the case cited earlier of the son who lived abroad. However, many carers were more closely involved in the day-to-day decisions about caring for the patient in hospital, such as deciding their dietary intake. Given the limited input of nurses in delivering hands on care, the importance of the family cannot be underestimated.

In contrast, health professionals mainly focused on decisions about treatment and examinations or medically or clinically related decisions. However, when these involved major risks or costs they usually took a backward step and placed the main onus on family carers. Interestingly, professionals also played a relatively minor role in decisions about rehabilitation, as this was often seen as the province of TCM. Compared to doctors, nurses seemed to take a rather more holistic view and talked of psychological counseling for carers, and also gave more attention to discharge and rehabilitation.

It will be apparent by now that a range of complex factors were at play in shaping who was involved in decision-making and when differing types of decisions were likely to be made. Attention is now turned to the type of knowledge and information that was used to shape decisions.

Types of Knowledge that were Used and Their Different Sources

In order to help them make the decisions required, all parties drew on a wide variety of information sources and often took a highly active role in explicitly searching out and using information. The major processes involved, such as 'seeking', 'sharing' and their variants form the substance of much of the next chapter and will be considered in far greater detail there. The focus here is on the types of knowledge utilised and these can be classified as follows:

- Specialised medical knowledge gained through communication with professionals (e.g. professional consultation/advice/explanations, one-to-one verbal discussions with health professionals, asking staff members, medical or nursing students questions)

- Knowledge gained from mass media which included different formats:

  o Written information, such as health education information, posters or flow charts on the walls or the notice boards; printed materials, such as patient information leaflets, magazines and newspapers and medical books;

  o Information presented in audio/visual materials, such as TV and radio programmes and health education video sessions presented on the ward;

  o Information in electronic format, such as on-line information posted on the Internet and web-based resources;

- Knowledge gained from their own prior health care related experiences (e.g. managing diseases, caring for patients, or using health care services):

  o Patients/carers often had prior experience of managing stroke or other types of diseases (e.g. diabetes, hypertension) which they had developed over many years;

  o Patients/carers might have their own experiences of caring for their older parents, parents-in-law or other relatives in an extended family who had stroke or other types of diseases. For example, taking relatives to hospital appointments, observing a relative's condition or looking after a relative;

Such individuals were often extremely knowledgeable and were likely to see themselves as co-experts. For example, patients especially those with long-term conditions saw themselves as experts of their own condition, and experts about management of their own condition, and took more control of their health and illness. Carers also saw themselves as holding expert knowledge of managing their relatives' long-term condition. Therefore, they saw themselves as

colleagues of health professionals, and usually played a major role in decision-making.

- Knowledge gained from their working lives - men were particularly likely to draw on job-related knowledge. For example, a husband who was a warehouse manager used his organizational skills to administer many different types of medications to his wife in a careful and conscientious way and closely followed the doctor's instructions:

> *Carer(3)15: "Since I am a very careful and conscientious person, so I can very clearly remember various medications which she needs to take, more than 10 kinds of medications, I think, no matter whether the dosage is one tablet, two tablets or half a tablet each time, I am very much clear about their dosages. She doesn't know about this information, and she isn't even clear about what medications she needs to take for her treatment. So I always prepare the medications for her and help her take them in our daily life at home.*
>
> *I think I am a very careful and conscientious person, and am always very careful to do everything. You know why, because I have been working as a manager for many years before I retired, and this is related to my working experiences…as a warehouse manager, I was required to work in a very careful and conscientious way, and I must do a very good job and keep everything well-organised rather than disorganised."*

Similarly, a son-in-law who was a hotel manager and routinely dealt with both people and financial matters was nominated as the major decision-maker within his family.

- Knowledge gained from their relatives'/friends'/colleagues'/neighbours' (e.g. managing their disease, caring for the patient, or using health care services)

- Knowledge gained from their relatives/friends/neighbours who were health professionals (e.g. doctors or nurses)

- Knowledge gained from other patients with stroke and carers sharing the same room or the same ward e.g. through face to face communication. In such

circumstances, stroke patients and carers who saw themselves as 'experts' shared their stories with each other.

- Knowledge gained from their wider social network (e.g. lay people encountered in their daily life)

- Knowledge gained from training (university courses for senior citizens, health education sessions or workshops organised by staff members in the hospital)

The findings suggested that access to diverse sources of knowledge and information played an essential role in helping patients and carers actively take part in decision-making and to feel more in control. Good information allowed them to effectively self-manage long-standing chronic conditions and to shape their everyday lives post stroke. Therefore, both patients and carers had a desire to locate and obtain information to satisfy their needs. As noted above, how they did this is the focus of the next chapter.

In addition to the factors discussed so far, a range of personal characteristics also played a major role.

Personal Characteristics and Other Patient/Carer Related Factors

Patients' and carers' personal characteristics such as their level of education, personality, gender, profession, age, ability to pay, and perceived competence to make decisions all played a major part in determining how actively involved differing individuals were. In addition, other factors such as peoples' understanding of stroke, the health insurance system and economic/financial circumstances largely influenced how patients/carers made treatment or examination decisions.

Patients/carers with higher education levels seemed to find it easier to make decisions, were more willing to make decisions, and played a more active role in decision-making. Patients/carers with lower education levels had far less confidence and were more likely to be passive. Professionals felt that higher education was also an indicator of willingness to accept health care interventions such as rehabilitation therapy:

> *Physiotherapist24(1): "Patients or carers may have different levels*
> *of acceptance towards rehabilitation which is closely related to their*

level of education. For example, some people have a lower level of education, and so have very little understanding about rehabilitation, and don't think that patients need to receive rehabilitation therapy given by the physiotherapist. They think that patients can take part in physical activity on their own, but don't need to receive physical therapy.

But some patients or carers have a higher level of education, so they can a have wider or more in-depth understanding about rehabilitation, and think that patients must receive rehabilitation therapy, rehabilitation is very important for patients' recovery. Just like those patients or carers who are university teachers, or primary school teachers, they believe that rehabilitation is very important for patients' good recovery. Even if the therapy is not covered by health insurance, they will still decide to give their relative the therapy, because they believe that rehabilitation is very helpful for patients' good recovery."

The findings suggested that patients' or carers' educational level potentially determined their sources of information and knowledge. People with higher educational levels were more likely to search for health related information through the Internet. For example, the son of one female patient was a university teacher, and he not only searched for information via the Internet, but also judged the trustworthiness of the information before using it to inform his decisions.

On the contrary, people with lower educational levels were more likely to search for health care related information through asking professionals, other patients or carers. This was especially true of those patients or carers who were from rural areas. Such individuals rarely mentioned using the Internet for gaining information.

Personality also played a role. Older people who were largely passive would follow their spouses' or children's advice or leave decisions up to them, so their family members largely made decisions. However, some patients were very self-determined and preferred to make their own decisions rather than follow other people's advice.

Similarly, personality also shaped the way in which carers made decisions. Those lacking in confidence or who were more inclusive would discuss decisions with the

wider family, whereas others preferred to act alone. This might sometimes cause family conflicts.

As noted above, men were more likely than women to use or draw on job-related knowledge (i.e. knowledge developed or gained from their daily working experiences) when making decisions with health professionals, and viewed decision-making largely as a 'job', suggesting potential gender differences. For example, the son of a female patient worked in a trade union and had developed sophisticated negotiation skills and he successfully used these skills to negotiate with doctors when he questioned their advice. He eventually reached an agreement with doctors whilst also maintaining a harmonious relationship with them. As will be seen later, the idea of maintaining harmony was very important to all parties.

The above data might be seen to reinforce a typical male dominance in terms of status and importance, but women also played major roles in decision-making, and this was often related to family cultures and patterns of decision-making as will he highlighted later.

Irrespective of gender, professional occupation also played a role and patients/carers who were in professional roles such as administrators or managers, teachers or health professionals preferred to make decisions, while those who were farmers were likely follow doctors' advice or leave decisions up to doctors.

Patients under the age of 60 preferred a more active role in making decision, and the younger the patient, the more likely they were to make decisions on their own.

Whilst a range of patient and carer related characteristics influenced decision-making patterns, the same was true of professionals. For example, doctors who were perceived by patients/carers to be highly competent and/or created a positive first impression were far more likely to be trusted by patients and carers. On the other hand, a poor first impression could have far ranging consequences on how trust was developed, as noted in the quote below:

> *Nurse(16)19: "Patients'/carers' first impressions about environment, doctors, staff's appearance, image, and language will influence their decision-making. If they have a very bad first impression, they may immediately decide to transfer to another hospital, and stop treatment here in our hospital."*

The influence of trust will be explored in more detail shortly.

All of the above factors influenced decision-making and provide insights into the complex constellation of issues that have to be taken into account. However, the data revealed a number of critical processes that were particularly influential and these are elaborated upon in the following chapter. As an introduction to this chapter two highly significant factors are considered in more detail here. These are the formation of trust between the major stakeholders and the role of culture in decision-making. The following section considers the role of culture.

The Role of Culture

The data indicated that culture was a complex and multilayered concept that operated at several levels and was one of the major influences on the decision-making process. At the most fundamental, and highly influential level were cultural beliefs and traditions extending over thousands of years that lie at the heart of what it means to be 'Chinese'. Starting from this very broad perspective, influences became progressively more focused until they related primarily to family patterns of interaction. The following section provides an overview of the view of culture, beginning with cultural 'mores' operating at a national level. At the heart of this, at least in so far as it is relevant to the present study, lies the traditional Chinese idea of maintaining harmony.

Maintaining harmony

Harmony has been a prominent theme in traditional Chinese culture, in particular Confucianism, in which harmony is highly valued as an important human ideal (Chen and Starosta, 1997). Confucian concepts of harmony not only describe how the world operates, but also act as moral precepts, prescribing how human beings ought to act towards each other (Li, 2008). According to Confucian philosophy, harmony can operate at different levels:

- Harmony operates within each individual, that is to say, an individual person can harmonise various parts of his or her body, mind, and how they pursue their life in order to be a well-functioning and whole person.

- Harmony operates between individuals at the family, community, national, and world level in order to achieve mutual support and interdependence. This may involve harmony within the same kinship, harmony within the same ethnic group with different kinships, harmony within a society with different ethnic groups, and harmony between societies.

- Harmony also operates between human beings and nature itself.

As can be seen the Confucian concept of harmony is comprehensive and by its very nature relational. Based on the Confucian classic work by Shi Jing, harmony is closely linked with human happiness, and the happy life is one in harmony with other people in society as well with the natural world (Li, 2008).

As a fundamental Chinese cultural value, harmony represents an ideal state which Chinese people pursue in their daily life and this deep-rooted belief strongly affects how Chinese people behave and guides them to make great efforts to establish conflict-free relationships (Chen, 2002). As will be seen in the next chapter this is highly influential in the decision-making process.

In the present study, the need to maintain harmony emerged as a key cultural dimension that was not only central within Chinese society as a whole, but also figured prominently in the health care setting. It exerted a significant impact on decision-making activities and the need to maintain harmony operated at three broad levels:

- Maintaining harmonious relationships,
- Maintaining a happy mood,
- Maintaining the whole body of a dead person (see Diagram 5.1)

The first two of these were particularly influential and as will be explored in the next chapter underpinned the two basic social processes operating to shape decision-making. The third of these, maintaining the whole body (harmony) of a deceased individual was most influential within certain nationalities within China and operated to determine whether or not certain invasive medical procedures were acceptable. This was particularly important for the Hui people or those who had the Hui nationality.

At an interpersonal level or from a social perspective, harmony was mainly about maintaining harmonious relationships between various groups of people, such as patients, their families and professionals so that disagreement and disputes which might result in 'bad feelings' were minimized.

At the level of the individual, the notion of harmony was mainly concerned with the internal harmony and well-being of a particular person so that their psychological health was not threatened or compromised. This was linked to a person's overall well-being and was closely associated with enhanced recovery from a major trauma such as stroke. As will be seen in the next chapter, the desire to maintain this sense of well-being was the primary motivation for keeping the older person in the dark (see 'Hiding' in next chapter) about any potentially 'bad news' relating to their progress. Although motivated by high ideals and genuine beliefs, this effectively precluded older people from a full role in the most important and far-reaching decisions.

Diagram 5.1 Components of Maintaining Harmony

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                    ┌─────────────────────┐
                    │ Maintaining Harmony │
                    └─────────────────────┘
              ┌──────────────┼──────────────┐
              ▼              ▼              ▼
┌──────────────────┐ ┌──────────────────┐ ┌──────────────────┐
│ Keeping a happy  │ │  Maintaining a   │ │ Keeping the whole│
│      mood        │ │   harmonious     │ │  body of a dead  │
│                  │ │  relationship    │ │     person       │
└──────────────────┘ └──────────────────┘ └──────────────────┘
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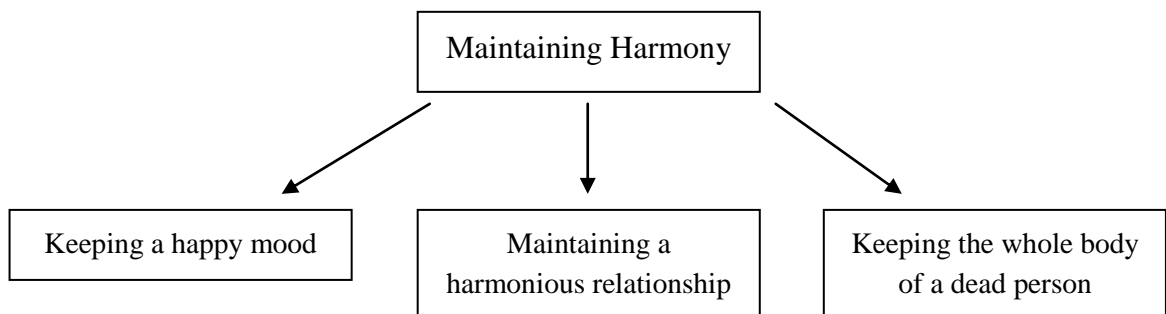
In addition to harmony, another major cultural belief that influenced decision-making was that of filial piety. In China, the Confucian philosophy promotes the cardinal status of the family in the lives of each individual, and considers the family as a central category and basic unit of social reality. The promotion of close familial bonds provides the family with a series of moral roles, responsibilities, and ritual practices that individual family member must undertake in order to make the 'good life' possible. Given this Confucian ideal, a 'healthy' family is considered as one in which all members exercise the virtue of mutual care of each other's health (Chen and Fan, 2010). Thus, the family occupies a central position in Chinese cultural tradition. In particular, one of the Confucian rituals seen to regulate appropriate human relations and interactions within the family is the familial practice of 'filial piety', which has been established as underpinning 'proper' family behaviour

throughout history, and provides general guidance about how 'good' families function (Fan, 2010). Consequently, children must be filial to their parents.

This might help to explain the central role accorded to the family within the decision-making process, often to the relative exclusion of the older person. The quotes below illustrate this:

> *Doctor 6(3): "Generally speaking, during patients' hospital stay, basically it is family members who make decisions for their patients. Because for example, in terms of examinations and treatments, we don't talk to patients about these issues, although they have the right to be informed, we generally seldom talk to patients, but always talk to their families and leave decisions up to families. Another example is about the decision-making regarding admission for a patient who comes to OPD to see a doctor. Sometimes the patient might say that if his or her family member decided that he or she needed to be admitted, he or she would follow their advice and stay in the hospital for treatment.*
>
> *Basically, I think, we often talk to families about patients' examination, treatment and condition, and ask them to make decision for patients…and issues (about which) patients need to be told generally include information such as how to prevent stroke through eating a healthy diet, taking certain medications, or living a healthy life style. We will give information about all these topics to patients."*
>
> *Doctor(8)1: "To me, decision-making means that, during the process of providing medical care, when there is a need to make some decisions regarding examinations, medical procedures, or treatments, we provide suggestions or information to carers, and then allow them to make a choice, or ask them to answer if they accept or refuse our suggestions. In our daily practice, basically carers will make decisions. Generally speaking, most of stroke patients admitted to our department are older patients, so the person who makes the decision may be the patient's older spouse or son or daughter. And also, in very rare cases, in which the patient is very stubborn, is a very assertive person, even though the carer wants to make decision*

for him or her but fails to do so, as a result, it is the patient who makes the final decision.

I also encountered a situation in which a male patient's children lived abroad and hired a helper to take care of their father, and the decision-making was not an easy thing to do, but very inconvenient. For example, for just a very simple procedure or decision, like gastric tube insertion, we needed to contact his son living in the US, and made quite a few phone calls, and left the final decision up to his son."

The husband and the son in law of a female patient shared their experiences.

Carer17(2): "I made the decision to transfer my wife to this hospital, for example…They needed to leave all the decisions up to me…Generally speaking, I don't make decisions in our family, but she makes decisions."

Carer18(4): "He (father in law) needs to make decisions on some major issues, for example, because my mummy has a very high fibrinogen level, so she needs to receive a kind of medication to lower her fibrinogen level…the doctor asks us to give signed consent. So in this situation, my daddy needs to make the decision and give his signed consent…In these circumstances, although I think my mummy can receive the treatment, we still must leave the final decision up to my daddy, and must ask for his permission before taking any action…Then afterwards, what we need to do is just to follow his decisions and implement his decisions. He is very much like a manager or a leader, and we follow his orders and do whatever he directs us to do."

The patient might also expect that her husband made decisions for her during hospital stay.

Carer18(15): "Actually my mummy makes decisions within our family. She very much prefers to make decisions in the family, and is quite short-tempered. On the contrary, my daddy is slow-tempered, has a good temper, and is not willing to make decisions. However,

now because my mummy has got a stroke, so many decisions are left to him.

She said to my daddy that 'you make these decisions related to my hospitalisation for me'. Therefore, in many situations, we need to leave the final decision up to him…She does hope that her husband makes decisions for her…she thinks that, if her husband knows everything about her disease and treatment, and makes decisions for her, then she will feel very safe, very confident and relieved."

Therefore, family members were found to be actively involved in care and decision-making activities not only throughout the patient's hospital stay but also during their recovery phase and daily life after discharge. They usually acted as the main decision-makers and were in control of information.

Given the Confucian account of the family as a whole and its appreciation of the familial bonds, it is not hard to understand why the family plays a crucial role in health care in a Chinese cultural context and why individual patients rarely make autonomous health care decisions.

<center>Cultural influences at a regional level</center>

With respect to making treatment related decisions, the findings indicated that distinct cultural factors exert an influence in different areas of China. For example, in Southern China an older patient's brothers/sisters usually pay any additional costs and are therefore influential in making decisions, whereas in Northern China it is children who do so and it is these individuals that play a major role in decision-making. A male doctor shared his understanding about how cultural influences varied by region,

Doctor(7)2: "In Shantou, a city in Southern China, if the parents have got the disease, their children will not pay health care costs, but patient's brothers or sisters will pay health care costs and make decisions. Their children may look after their parents, but the main financial support is provided by the parents' brothers or sisters. But in Northern China, basically the patient's direct relatives like children will pay the costs and make decisions".

Cultural influences operating at the professional level

The idea that maintaining harmony contributed to good recovery and maintenance of health was not only an aspect of Chinese culture in general, but was also deeply ingrained in professional culture, both as a consequence of national beliefs and health care training. Consequently, disclosing bad news to patients was seen to be detrimental to recovery and might result in deterioration in their health or even result in their death.

As a result, professionals were reluctant to give a poor diagnosis, prognosis or disclose negative information to patients (such as, a diagnosis of cancer, severe stroke condition, life-threatening risks associated with a certain type of treatment, or a poor prognosis). As will be seen in the next chapter, this often meant that patients were excluded from major treatment decisions, with this responsibility passing to family members.

However, in certain circumstances, professionals might provide information about a poor prognosis to patients, especially those who had a higher education level or adopted an optimistic attitude towards their lives. Such individuals were therefore much more involved in the decision-making process.

> *Doctor(1)19: "In exceptional cases, or in rare cases, doctors can talk to patients about their disease conditions, such as cancer or severe stroke. For example, some patients have higher education level, or are very optimistic about their life, or hold a very positive perspective or attitudes towards their life, they are very much anxious to clearly understand about their disease condition, they also hope that doctors can instruct them how to positively and actively receive treatment and rehabilitation and how to actively fight against or manage their diseases.*
>
> *So for these patients, doctors may tell them the true information about their condition, in order to allow them to actively face up to their diseases and take appropriate interventions accordingly."*

The influence of team culture

As well as the pervading professional culture, differing health care teams often had their own ways of working that influenced patterns of communication and the hierarchy of relationships. What might be called 'team culture' was usually determined by the senior medical practitioner and the way that he/she interacted with patients and carers. This was especially apparent during the ward rounds that I observed. An indication of how differing patterns of working could influence decision-making and relationships is provided below.

Communication patterns facilitating decision-making and potentially promoting harmonious relationship between professionals and patients/carers

- During ward rounds staff demonstrated a positive attitude towards patients and carers, by smiling at them, listening attentively, leaning forward, maintaining eye contact, speaking slowly and clearly and allowing patients/carers time to ask questions. These non-verbal behaviours encouraged patients/carers to ask questions and to raise any concerns that they might have. They therefore resulted in a more active role in decision-making.

- Staff actively sought and shared information (see next chapter), and spent time closely observing a patient's condition, communicated frequently with patients/carers, both asking and answering questions, as well as giving detailed and clear information and explanations. This again encouraged far greater participation by patients and carers.

- When doctors were not very good at giving information to patients/carers, nurses would often take on this role and ensure that people had the necessary information to play an active role in decision-making.

Communication inhibiting decision-making and potentially compromising harmonious relationship between professionals and patients/carers

- As a matter of course, doctors rarely involved patients/carers in decisions about routine examinations or treatments that did not involve either risks or costs. Rather they made such decisions and then informed patients/carers. Therefore in these circumstances, doctors exercised absolute authority, and played a dominant role in decision-making.

- Whilst the above was common practice for routine procedures some professionals took a dominant role in all circumstances. They demonstrated behaviours that actively inhibited participation such as: interrupting patients/carers when they were talking; making unilateral decisions about treatment options; being unwilling to clarify their meaning when patients/carers were unclear; using complex language or speaking very rapidly. In addition, they tended to avoid eye contact and demonstrated impatience by turning away or frowning when patients/carers sought further clarification. The role-modeling of such behaviours by senior practitioners ran the risk of them being adopted by junior colleagues. Not surprisingly, in the face of such behavior most patients/carers remained largely passive.

  For example, when a male patient came to the doctor's office to talk to his physician about his progress, its treatment effect and how long he still had to stay in the hospital, the physician spoke to the patient very quickly, gave short answers, avoiding detailed explanations. When the patient further asked her questions in order to clarify whether he accurately captured her meaning, the physician did not look at the patient, but rather before the patient's questions were fully answered, or his concerns were all explained, the physician started to talk to other colleagues and ignored the patient.

  In the above example, the physician's behaviours clearly reflected her impatience and unwillingness to communicate with her patient and as a result the patient did not have adequate information upon which to make an informed decision.

  Similar situations arose with nurses, especially when they were busy doing other work. For instance, when the office nurse was busy managing records or dealing with documents, if a patient or carer came to ask her questions, she might demonstrated her impatience by talking quickly and avoided eye-contact.

- Some doctors who led ward rounds talked to colleagues in front of the patient/carer as if they were not there.

- During ward rounds, some doctors spent more time communicating with carers rather than patients even when patients clearly wanted to join the discussion. In these cases, patients were often ignored and excluded from decision-making.

Family culture and decision-making

Family patterns of working and communicating had a number of influences on decision-making process, especially when the decision was perceived to be a difficult one that might cause potential conflict within the family or result in a high risk scenario for the patient. In many families, there was someone who usually took the role of decision-maker (sometimes the patient but for reasons already alluded to this was rarely the case with regards to health care) and in routine cases the usual pattern of decision-making was followed. However, in cases of difficult decisions the main decision-maker usually consulted widely with other family members (e.g. his or her brothers or sisters, or other relatives), asking for their advice and discussing options in order to reach an agreed decision, avoid conflict, and so maintain harmony within the family.

Such decisions could involve a patient's nursing home placement after discharge, whether to accept an operation or other treatments involving risks for the patient, or whether to stop treatment or withdraw a patient's life support. Therefore, maintaining harmony between members of the family system was another facet of the decision-making process.

> *Carer(1)1: "Sometimes I need to call other brothers and sisters to ask them how to do and what to do, whether they agree with me, what their suggestions are. If they agree with me, I will give my signed consent…I can't make decisions on my own when I need to give the signed consent, such as using medication involving risks…since if some problems happen, I will not know how to explain, because people may think that 'how come you can have the final say', and will be very unhappy. The communication between family members is very important, if I don't communicate with other family members, some conflicts or problems may happen."*

The daughter of a female patient talked about how decisions were made for her mother during hospital treatment and how culture played an important role at the family level:

> *Carer(19)6: "Since there are many people in our big family, so the way in which we make decision for our patient here during her*

hospitalisation is that we have a discussion between family members before making a final decision. Actually, we have the similar decision-making style in our family, for example, if we need to make a decision in our daily life, we will also have a discussion between each other.

Because we have a democratic working style in our family when we need to make decisions, so we don't leave the decision up to a particular family member, but rather, we follow the decision which is considered as the most appropriate one by most of us."

The data indicated that family carers tended to follow an established pattern of working and adopted the way in which decisions were usually made in normal daily life when they needed to take responsibility for the patient.

Interestingly, it seemed that there was no particular individual who took prime responsibility for major treatment-related decisions, since these types of decisions were made through discussion amongst multiple family members, in order to maintain harmony.

Where there was no extended family or the family clearly had one member who routinely made all the decisions in the family this pattern was also normally followed. Interestingly, the data indicate that this was not always the senior male figure, as in traditional Chinese culture, but could often be a younger daughter if they were seen to have the expertise required or were likely to end up paying for any additional costs.

<div align="center">The influence of personal values and beliefs</div>

Participants' personal values and beliefs also impacted on their decision-making behaviours. Some carers who held specific religious beliefs, such as Buddhists, felt that to die peacefully was important and so they would refuse invasive or radical interventions or procedures. Carers who were Muslims were also reported to tend to refuse invasive examinations/treatments for their dying patients, and to request discharge so that they could die at home.

Doctor(2)10: "Patients'/carers' decision-making behaviours during hospital treatment may perhaps also be determined or influenced by

their religious beliefs…Buddhists don't think that death is the end of life, but is only the end of one cycle of life and the start of the next cycle. So they pay much attention to the whole process of dying and death, and will not think that many emergency rescue interventions are really useful, helpful or meaningful for saving patients' life.

They will therefore believe that to die peacefully is most important for patients. So they may refuse invasive or radical treatment interventions or examinations which may cause pain to patients, such as electrical defibrillation of the heart, tracheal intubation, or puncture procedures, and may choose to let their patient die at home or at a place which is familiar to the patient."

Equally, a doctor's personal beliefs might influence their involvement of patients or carers in decision-making. Doctors who personally believed that they were the expert and knew best, were unlikely to actively involve patients/carers in decision-making.

Culture, values and beliefs clearly played a major role in shaping decision-making in the acute care setting and as illustrated above operated at a number of levels. However the influence of maintaining harmony was often pre-eminent and exerted the major influence. Closely related to harmony was the importance accorded to developing trust.

Developing Trust

The findings suggested that central to maintaining harmony and reaching agreed decisions between patients, carers and professionals was the role of trust. Developing trust was considered by participants as being closely interrelated with keeping the peace in relationships (see next chapter) as trust was an essential prerequisite for relationship building:

Doctor(7)15: "I have a partnership with my old patients, I mean the partnership doesn't necessarily only exist between colleagues, it can also be established between doctor and patient and their carers when they get along with each other for a long time. For example, the patient often comes to see me when he has health problems, he trusts me very much, then both of us can establish a partnership,

because to have a good partnership must require trust. Then the final decision being made is usually an agreed and mutually accepted decision."

In order to create and maintain a harmonious relationship, patients, family carers and professionals sought to establish trust by maintaining regular contact and working together to develop mutual understanding and respect.

There was a dynamic and reciprocal interaction between the development of trust and harmonious relationships that people worked hard to achieve. For example, a husband described the important role of a harmonious interpersonal relationship in building trust:

> *Carer(17)12: "The harmonious relationship between people is very important…if the hospital has a very good atmosphere where people all have a very harmonious relationship between each other, then the professionals will be able to provide quality services to patients and carers, and meanwhile…more patients will come to this hospital for treatment rather than to other hospitals…we trust this hospital and its staff, we feel very relieved during the hospitalisation, since there is a good atmosphere and a harmonious relationship among people."*

The development of trust was therefore a pre-requisite to positive decision-making. For example, in order to both develop and demonstrate their trust, patients or carers would seek advice from professionals or other family members, or provide clear and complete patient information to doctors; doctors and nurses would actively give advice or explanations to patients and carers, or seek information from patients or carers. These activities of 'seeking' and 'sharing' are two of the core categories to emerge from the study and will be described fully in the next chapter.

In order to help develop trust and foster harmonious relationships, staff, patients and carers used a variety of strategies, including:

- Giving detailed information and clear explanations about the progress or prognosis of patients' disease and possible outcomes (as already alluded to and to be elaborated upon in the next chapter, patients were often excluded in cases of a poor prognosis);

- Having lots of patience;
- Being confident;
- Answering questions;
- Knowing the patient well;
- Respecting each other;
- Allowing patients/carers to spend time talking about the patient's health condition and their concerns;
- Providing effective treatment to improve a patient's condition;
- Communicating frequently with patients/carers;
- Maintaining long term engagement and regular and frequent contact between each other

However, trust did not simply operate at an interpersonal level as patients and carers also wanted to trust in the hospital itself and a range of differing treatment options such as TCM. The role of trust, as with culture, therefore operated at differing levels and at varying points in the patients/carer journey, beginning with the choice of a hospital.

Patients'/carers' trust in a hospital

The findings demonstrated that patients and carers usually chose a hospital that they trusted or where they trusted the doctors. Conversely, if this trust proved unfounded they would transfer the patient to another hospital.

> *Patient(10)1: "I can choose which hospital to go to see a doctor, and choosing a particular hospital demonstrates your trust towards this hospital."*

> *Patient(18)6: "When I come to the hospital to see a doctor, this means that I trust this hospital, trust the doctor, and put myself in the doctor's hands."*

> *Doctor(7)2: "The patient has a large amount of bleeding, but since the carers don't trust our hospital, therefore they would like to transfer the patient to another hospital which is a specialised hospital for cerebral vascular disease."*

Doctor(9)5: "Sometimes, when the patient can't get good treatment effect in a certain hospital, such as a lower level hospital, or a community hospital, the patient and carers will not trust that hospital, then the carers will transfer their relative to our hospital, to a higher level hospital, since they trust us, trust our hospital."

Patients'/carers' trust in professionals

Participants mainly talked about how trust in their doctors played an influential role in making decisions. It was suggested that the more patients or carers trusted doctors, the more likely they were to decide to come to the current hospital for treatment, cooperate with doctors, ask for and follow doctors' advice, have better compliance, give signed consent, or even leave decisions completely up to the doctor. The son of a female patient and a physiotherapist gave the following comments:

Carer2(1): "I trust doctors, why, because I don't understand medical knowledge. Here in the hospital, doctors are experts, so I put my patient in the hands of doctors, doctors have better knowledge and skills than I, so I trust them…If I don't trust doctors, I will not choose to come to this hospital to get treatment for my patient."

Physiotherapist24(3): "Some patients or carers trust health professionals very much when they come to the hospital for treatment. For instance, they would like to do whatever doctors ask them to do, or to accept any treatments if doctors say that those treatments are good for patients. These patients or carers don't know much about the patient's condition, and don't have medical knowledge, so they trust doctors very much. Since they trust doctors, so they believe that what doctors do must be in the patient's best interests, therefore they decide to fully follow the doctors' advice."

Doctors generally agreed suggesting that the more patients or carers trusted their doctors, the more likely they were to actively participate in decision-making activities.

However, those participants who had less trust were found to be more likely to ask the doctor questions, question the doctor's advice, check with other people about

the doctor's suggestions or consult other people (e.g. other professionals, relatives, or patients), hesitate in making decisions, or make decisions on their own rather than leaving decisions up to the doctor.

In addition, the findings highlighted the potential role of other patients/carers in building trust. Patients/carers, especially those sharing the same room, often exchanged information or comments through chatting to each other about a particular staff member's performance which could potentially influence the establishment of their trust in health professionals (see next chapter for a fuller discussion).

For example, positive information or comments about a particular doctor given by other patients/carers might enable the current patient and carer to trust that doctor and want to see him/her for treatment. On the contrary, the current patient and carer might not trust the doctor and not want to see him or her due to hearing about the poor comments given by other patients/carers.

> *Doctor(1)11: "Patients also can influence each other. For example, patients sharing the same room may talk to each other to give comments about how effective their treatment is, how good the doctors are, then other patients who hear about these types of information will have more trust in their doctors...the patients living in the same room will have influence on each other's decision-making behaviours since they may have a chat with each other and talk about doctors.*
>
> *If there is one patient in this room who is unsatisfied with a doctor, or has conflict with a doctor, then this patient may complain to other patients about how bad that doctor is, this also can influence other patients' decision-making.*
>
> *Or in other cases, if some patients feel dissatisfied with a doctor, the old patients sharing the same room will help explain to those unsatisfied patients, they may say that 'the doctor is very good, we have stayed here for a long time, or we have come to this hospital many times, so we know that the doctor is a good doctor', then this will allow the unsatisfied patients to have more trust in their doctors."*

Doctor(3)7: "Patients sharing the same room will communicate with each other, or have a chat with each other, this will influence their decision-making activities, the information that they exchange will have an impact on the choice they make. For instance, two patients of mine stay in the same room and trust me very much. Then when the third person who is also my patient comes to stay in this room, those two patients will share positive comments about me with the third patient, tell him or her how they trust me, and allow him or her develop trust in me. However, if one patient doesn't trust me and is unhappy with me or my performance, he or she will also let other patients know, and the consequence is that other patients will not trust me anymore."

Patients' trust in carers

Given the fact that the majority of the most important decisions were usually made on the patients behalf by the family (either one member or via discussion) then it was important that the family members involved had the trust of both the patient and the wider family.

Carer(18)17: "My wife and I have been married for about 20 years, I think that during such a long period time, my parents-in-law gradually come to think that I am a good, very capable and thoughtful person, who can thoroughly take everything into consideration when making decisions. Therefore my parents-in-law very much trust me and think that my decision or choice must be a good one, and also trust my decisions."

Similarly, the more the patient trusted the carer, the more likely he or she was to follow the carer's advice or leave decisions up to the carer. For example, a wife (i.e. the patient) trusted her husband, and so wanted him rather than her children to make decisions for her.

Carer(18)16: "My mother does hope that my father makes decisions for her. Because from her personal point of view, children will never be better decision- makers than her husband…she trusts her husband very much, she thinks that, if her husband knows everything

about her disease and treatment, and makes decisions for her, then she will feel very safe, very confident and relieved."

Patients'/carers' trust in TCM

A number of patients/carers had considerable trust in TCM and so chose to receive acupuncture therapy or TCM medication, to be transferred to TCM hospital for treatment, or to go to TCM hospital for rehabilitation after discharge. Some carers decided to seek a second opinion from a TCM doctor during the patients' hospital stay, as illustrated by the following descriptions given by the daughter of a male patient and an acupuncturist:

Carer5(15): "I once said to the doctor and required him to invite a TCM doctor to come to see my father, and to prescribe some Chinese herbal medications for him. The reason is that I think, after discharge he will keep on taking medications for a very long time, so I think taking traditional Chinese medications for treatment is more reliable, safe and appropriate for him…Afterwards the doctor met my request and invited a doctor from the department of integrated TCM and western medicine to come here to see my father."

Acupuncturist25(1): "Patients and carers very much trust TCM, like herbal medication, acupuncture, they generally all know about TCM, and know that acupuncture is one of the effective treatments for stroke patients. Most people know about these TCM treatment interventions…some patients, they might have had other types of diseases in the past and have received TCM treatments, so they very much trust TCM. Sometimes, patients or carers might say to me that they very much trust TCM and look forward to receiving TCM treatment.

I also think that the more patients trust TCM, the more likely they are to cooperate well with me, and the better their treatment effects are. If they would like to receive acupuncture, they like TCM, then they would have better effects. Since patients or carers trust acupuncture, so they would like to decide to accept acupuncture therapy."

Patients'/carers' trust in information

As noted earlier patients/carers often sought a variety of information from a number of different sources and had varying degrees of trust in this. For example, some patients/carers trusted online information especially that provided by several big websites, some trusted the information delivered in TV programs, books or newspapers, and some trusted information or explanation directly provided by health professionals.

> *Carer(2)8: "Communication tools and information exchange are very effective and convenient, I can find some information through searching the Internet...like something about health maintenance, health promotion, how to carry out functional exercises…I can get online information from several big websites, if their explanations are consistent, I will trust the information, otherwise, I will not trust all of them."*

Professionals' trust in patients/carers

Although it was clearly very important that patients/carers trusted health care professionals, especially doctors, this was not a 'one way street' and trust also influenced the way in which professionals worked with patients/carers. It was reported that if doctors trusted patients/carers then a good relationship was more likely. For instance, if doctors trusted patients' histories and believed that patients had reported accurate information about their condition, then they would be able to make an accurate diagnosis and give correct or more appropriate treatment, which could further have a positive impact on patients' recovery and finally lead to better patient outcomes.

Furthermore, professionals' willingness to provide detailed and clear information was influenced by the perceived trustworthiness of carers or patients, and staff might either exaggerate or downplay the degree of risks in certain circumstances. For example, doctors might give more information about conservative or the safest treatment or conversely highlight or over-emphasise the risks associated with radical treatment when talking to carers if they didn't trust patients and carers to understand doctors' treatment plan, follow doctors' advice, be willing to give informed consent and be responsible for their decisions and outcomes, but rather they believed that patients or carers were very picky and likely to blame

professionals if things might go wrong.

On the other hand, if doctors thought that the patient or carer was trustworthy, they tended to give more information about radical treatment interventions even if they had potential risks.

> *Doctor(1)13: "Doctor's trust in patients and carers is also important...I find that some patients have very good adherence, understand your explanations, actively cooperate with you, so I trust them...I will try to tell them about anything or any treatment which is good for them, even though we may need to take the risk, patients and carers and I together may need to take the risk, I will tell carers about risks and give patients the best treatment.*
>
> *If I don't trust them...like sometimes the patients are very picky about details and little problems, I may give conservative treatment or use the safest treatment, I don't want to cause any problems or get into trouble, therefore I give the safest treatment...I will provide them information about the safest treatment which is usually covered by the health insurance and doesn't involve any risks."*

Summary

During the period of 2-3 weeks in hospital, patients, carers and staff were involved in making many, often complex, decisions, which were influenced by a wide range of important contextual and background factors.

The study suggested that some decisions were led primarily by professionals, others by family members and others were made between three groups (i.e. patients, carers and staff). Others who might play a part included other patients and carers sharing the same room or the same ward, friends or neighbours who were health professionals or had similar diseases, as well as other social network members.

The types of decisions that were made varied over time, and were influenced by a complex array of factors depending on the stage of the patient's journey. For example, hospital reputation, distance between patient's home and hospital, and quality of physical environment were the major considerations for hospital selection or help seeking decisions; while risk/cost, urgency of patient's condition, and

treatment effect would have an impact on decision-making activities during the hospital stay.

Patients, carers and professionals sought to gain the information and knowledge necessary for decision-making from a variety of different types of sources and the personal characteristics of patients/carers (e.g. educational level, personality, gender, profession, patient's age, carer's getting legacy, carer's ability to pay, carer's perceived competence to make decisions, understanding about disease, health insurance coverage, and economic/financial condition) and professional related factors (e.g. doctor's experience, perceived seniority of doctor, first impression about a doctor given to patient/carer, and staff expertise or quality of service) all exerted an influence on decision-making.

The findings indicated that culture played a central role in shaping people's decision-making experiences, and operated at different levels such as national level, regional level, professional level, team culture, family level, and personal level. The Chinese cultural ideal of maintaining harmony exerted the most influence on decision-making activities, and acted as the key motivation underlying many subtle behaviours. There were three dimensions to maintaining harmony which included maintaining a harmonious interpersonal relationship, maintaining a happy mood, and maintaining wholeness of the body. The influence of harmony on the basic social processes underpinning decision-making will be elaborated upon fully in the next chapter.

Equally important to maintaining harmony and making-decisions was the idea of developing trust. This comprised a number of dimensions such as patients'/carers' trust in the hospital, patients'/carers' trust in professionals, patients' trust in carers, patients'/carers' trust in TCM, patients'/carers' trust in information, and professionals' trust in patients/carers.

The next chapter will describe the two core categories and consider how they are interacted in light of the important contextual and background factors and issues discussed above.

CHAPTER 6: FINDINGS PART TWO

THE CORE CATEGORIES AND THEIR INTERACTIONS

Introduction

In the previous chapter a wide range of background and contextual factors shaping decision-making were highlighted, especially the crucial role played by maintaining harmony and building trust. In this chapter, the core categories identified in the present study and their interactions in the light of the factors previously highlighted will be the primary focus. I will describe the core categories with the aid of diagrams and build up the resultant theory step by step. This will unfold as follows:

- Firstly, the core category of *'keeping the peace'* will be outlined. This comprises the two dimensions of: '*keeping peace of mind'*, and *'keeping peace in relationships'* to include inter-professional relationships, inter-familial relationships, patient-carer-professional relationships, and relationships between patient/carer from different families;

- Secondly, the second core category of '*making decisions'* is presented including the key social processes of *'hiding', 'seeking' and' sharing'* and their specific sub-categories to include for *'hiding'*: permanent hiding, temporary hiding, and tailoring to hide; for *'seeking'*: searching, watching/comparing, and checking; and for *'sharing'*: informing, advising, exchanging, and tailoring to explain.

- Thirdly, the whole theory, illustrating the dynamics between the two core categories of *'making decisions'* and *'keeping the peace'*, and the major factors shaping decision-making processes will be presented.

- Finally, examples of making certain types of decisions are used to illustrate the dynamics operating between *'making decisions'* and *'keeping the peace'* and other important factors.

Central to all of the above is the goal of *'keeping the peace'* which reflects the deeply embedded nature of the Chinese cultural ideal of 'maintaining harmony'. For this reason the core category of *'keeping the peace'* is considered first.

'Keeping the Peace'

As data analysis advanced, the first core category to suggest itself was that of *'keeping the peace'*. This was primarily influenced by the deep-rooted Chinese cultural ideal which dictates that people maintain harmony in their daily life and in society. In the context of decision-making in stroke the data indicated that *'keeping the peace'* comprised two major dimensions; *'keeping peace of mind'* and '*keeping peace in relationships'* (see Diagram 6.1).

At a personal level, especially that of the patient, *'keeping the peace'* referred to efforts made to maintain a person's peace of mind or happy mood. The belief that there was a close link between a person's mood and a good recovery was widely accepted by patients, family carers and health professionals, and was the most fundamental reason behind their desire to maintain the patient's mood. As will be illustrated later in order to promote a patients' recovery through maintaining their peace of mind, professionals and carers often deliberately hid negative information about a poor prognosis or treatment involving risks from patients. This effectively precluded the majority of older patients from playing an active role in decision-making.

At an interpersonal level, '*keeping the peace'* involved numerous efforts to ensure that harmonious relationships were maintained at a variety of levels, as illustrated below:

- Inter-professional relationships concerned those between the various professionals within a health care team.

- Inter-familial relationships were those between the patient, his or her carers and other family members or relatives in particular within the same family. The goal was to achieve consensus where possible, and avoid potential conflicts or blame.

- Relationships between professionals, patients, and carers during the patients' hospital stay or throughout the whole patient journey.

- Relationships between patients and carers sharing the same room or the same ward with other patients/carers.

'Keeping the peace' within these relationships often involved complex and diverse compromises that also exerted a considerable impact on the way in which decisions were made.

Diagram 6.1 The Core Category of Keeping the Peace
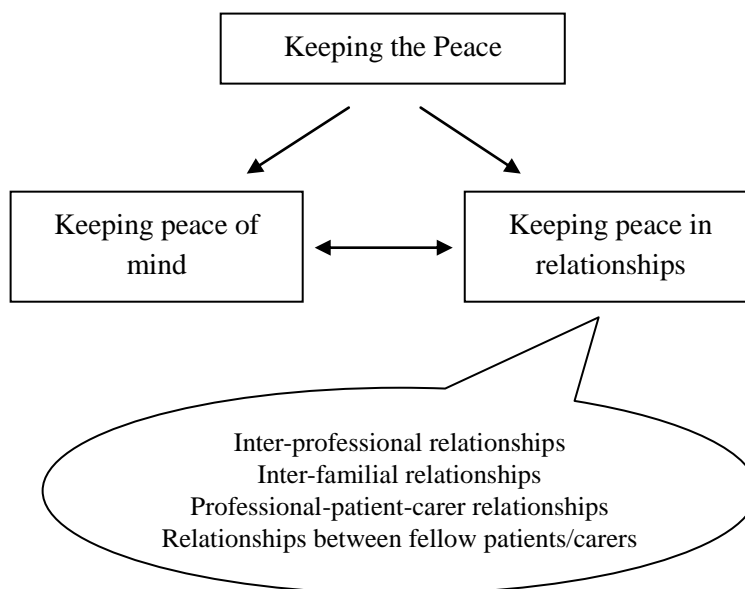
Making Decisions

The second core category was termed *'making decisions'* and captures several basic social processes that shaped the way that older people, carers and professionals made decisions. As will become clear there was a dynamic relationship between the core category of *'keeping the peace'* and the social processes of *'hiding', 'seeking'* and *'sharing'*. These latter processes describe patterns of communication and efforts to either, hide, seek or share information between the various parties involved. Each of these basic social processes also comprised sub-processes as follows:

- Hiding: permanent hiding, temporary hiding, and tailoring to hide were subcategories of the hiding process;
- Seeking: searching, watching/comparing, and checking were subcategories of the seeking process;
- Sharing: informing, advising, exchanging, and tailoring to explain were subcategories of the sharing process.

Three groups of participants were all actively involved in each of the three key processes and they acted in a reciprocal and dynamic manner in tandem with the types of decision to be made, the knowledge needed to make it and the stage of the stroke journey, as will be demonstrated. This dynamic is illustrated in the figure below.

Diagram 6.2 The Core Category of Making Decisions
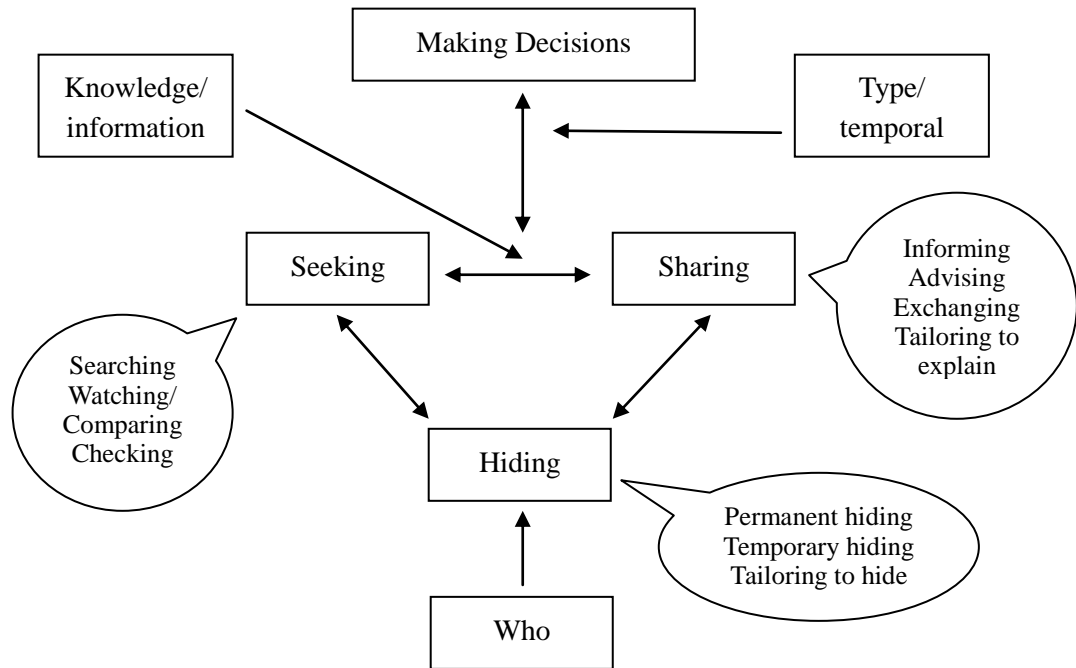
Probably the most telling dynamic was that which existed between *'hiding'* and the desire to *'keep the peace'*. This is therefore considered first.

'Hiding' and 'keeping the peace'

Hiding behaviours were identified amongst all three groups of participants and the goal of these behaviours was to prevent the full disclosure of certain information or mask the truth about something. As will become clear the rationale for this was primarily to *'keep the peace'* and thereby maintain harmony. Whilst all three groups of participants used 'hiding' it was far more common amongst professionals and carers and its impact, although largely unintentional, was to effectively preclude patients from involvement in some of the most important decisions. Under the category of *'hiding'*, three sub-categories were identified: (1) temporary hiding; (2) permanent hiding; and (3) tailoring to hide.

Temporary hiding

Temporary hiding, as the name suggests, comprised behaviours used by patients and carers for a relatively short period of time rather than during the whole stroke journey. It involved the temporary withholding of certain information from others.

- Patients' temporary hiding behaviours

There were a number of examples of patients using temporary hiding behaviuors. In some instances they temporarily hide the truth about their disease and/or hospital treatment from certain family carers. For example, to prevent their older spouse from suffering fears or anxiety they might not inform them about their initial symptoms until they became too severe to ignore. Whist this was intended to *'keep peace of mind'* it could delay help-seeking behaviours. On the other hand, older patients together with their older spouse might decide to temporarily hide information about the patients' condition and hospital admission from their children due to their reluctance to 'bother' their children.

In both situations, patients needed to make judgements about the timing of information disclosure but hiding information in this way, rather than resulting in *'keeping peace of mind'* might have the opposite effect. Below a son-in-law described what happened when his mother-in-law became ill:

> *Carer(18)6: "My parents-in-law are very reluctant to bother their children. For example, they didn't let us know that my mummy got sick until she had already been admitted to the hospital. At that time, my mummy didn't allow my daddy to tell us that she got sick and was hosptialised, because she didn't want to trouble her children for help."*

- Carers' temporary hiding behaviours

Sometimes carers would unilaterally decide to hide information about the hospitalisation of a family member, as in the case of a husband not informing his daughter of her mother's admission:

> *Carer(21)4: "When my mother was sick, my father didn't immediately tell me this. He didn't call me until 2:00 am the next*

morning…the reason why my father didn't immediately and timely tell me that my mother was sick was that he didn't think that my mother had a very serious disease, but he thought that my mother would spend at most several days staying in the hospital for treatment and then make a full recovery. I was told by my father later that he didn't think that my mother was in a serious condition, so he decided not to inform me immediately."

Again it is unclear whether the intent 'not to bother' children and thereby *'keep their peace of mind'* was entirely consistent with the children's wishes.

Temporary hiding was however usually less problematic than permanent hiding.

Permanent hiding

Permanent hiding processes were used widely by patients, carers and professionals and involved totally keeping certain information from other people. Examples of this by all groups are presented below.

- Patients' permanent hiding behavior

Permanent hiding was used far less often by patients than it was by carers and professionals. The most usual form was for patients to be less than frank with doctors about their prior medical history, especially if this suggested that they had been engaging in socially undesirable behaviours. For example, a male patient hid his history of having pancreatitis from his current doctor as this was associated with his prolonged and heavy drinking habit. This was noted by a patient that he was sharing his room with:

Patient(5)3: "The patient in bed #2…previously once had pancreatitis, but when the doctor asked him about his disease history, he didn't tell the doctor about this information…but only recently, he told the doctor that he once also had pancreatitis in addition to his cerebral infarction. The doctor then asked him why he didn't tell the doctor earlier about his disease history…doctors identified his problem with his pancreas based on his result of a scan which he had received before he finally told the doctor the truth about his disease history."

The motivation here seemed to have been to *'maintain face'* with the doctor, another important Chinese cultural value and important to *'maintaining peace in relationships'*. However, in this instance it backfired as the doctor discovered the pancreatitis from the scan and therefore the patient 'lost face' twice by having initially 'hidden' the information and subsequently being found out.

Other examples suggested that patients sometimes failed to listen to a doctor and preferred to take lay advice instead. This could lead them to stopping their medication, something that they understandably then wanted to 'hide'. Unfortunately the consequences could be serious, as illustrated below:

> *Doctor(6)29: "When making decisions, some patients also follow advice from lay people. For instance, I once had a patient, who had had no recurrence of cerebral infarction over three and half years. He was a breakfast-seller, and sometimes, some clients said to him 'look, you have such a good recovery from your stroke, how long have you had no recurrence since discharge last time?' He said 'already three and half years.' The clients said 'you have had no recurrence for quite a long time, so now you don't need to take any medications.'*

> *Actually the clients are just lay people who buy their breakfast, but are not doctors, are not health professionals, but the breakfast-seller really followed their advice and stopped taking his oral medications.*

> *However, unfortunately he suffered from a stroke once again only half a year after he stopped his medication. He came to see me for treatment and was found to have large area cerebral infarction...You know, he hadn't come to me for medication prescription for quite a long time, I assumed that he bought medications by himself at the drug store.*

> *Then I asked him 'I haven't seen you for a long time, what have you been doing? And where do you buy your medications?' You know, he didn't dare to tell me the truth that he had stopped his medication based on his clients' advice. After that his wife said to me 'I hope this won't make me feel too embarrassed, to be honest with you, he*

stopped taking his oral medications.' I said 'why did he do that?'
Then his wife told me the truth."

- Carers' permanent hiding behaviours

Like older patients, family members would use hiding behaviours but in a larger number of different situations, sometimes permanently hiding certain types of information from patients' spouses, other relatives, health professionals, and most importantly from older patients themselves.

- o Hiding information from patient's older spouse

Family carers, in particular patients' children, often hid bad news from their parent's spouse and therefore only selectively involved their older parents in decision to be made. Such information usually included a patient's poor diagnosis or treatment or examinations which involved considerable risk. This reflected the adult child's unwillingness to increase their older parents' anxieties, fears, or concerns and thereby compromise their 'peace of mind'. In the following example, the son of a male patient took his mother's personality and potential reaction into consideration, and decided to hide information from her:

> *Carer(1)4: "Since I think that my mother will be frightened if we discuss with her about making decisions on using the medication which can cause risks for my father…so we didn't discuss with her about this. She is a very timid person, if we tell her that the medication can cause risks to my father, she will have a lot of concerns…and may not be able to sleep well, so we don't tell her about these decisions and these sorts of things, I don't think she needs to know about these sorts of things, which can make her have lots of concerns."*

- o Hiding information from other relatives

In addition to hiding information about the patient's condition from their spouse, family carers could hide such information from other relatives. For example, the son of a male patient said that the last time his father got sick and was admitted to the hospital, he notified many relatives about his father's condition and admission, and so lots of people came to visit his father. However, this time when his father got

sick and was hospitalised, he didn't tell many people about this news, since he did not want them to feel obliged to visit his father.

- o Hiding information from professionals

Family members often hid the truth about their financial difficulties from health professionals such as their doctors, as they did not wish to 'lose face' by revealing their inability to pay for potentially expensive investigations or procedures. They might further 'hide' this by providing another 'reason' for not wanting certain procedure undertaken. For example, according to some doctors, sometimes carers might refuse tracheotomy and tell the doctor that this was because they wanted to maintain the whole body of their dying patient. However, the real motivation for refusing treatment was that they were unwilling or unable to continue spending money on further interventions. Conversely, they might justify a refusal to accept further treatment because they believed it be too high a risk, when the underlying reason was a lack of the necessary funds. Doctors were often aware of this and the failure of the family to provide the real explanation could erode trust and compromise relationships between carers and professionals:

> *Doctor(15)5: "Sometimes the carer or patient does have financial problems, but they don't directly refuse the treatment by saying that they can't afford the cost, and they may find other excuses or give other rationales for refusing the doctor's advices. So in this case, the real reason behind perhaps was due to the financial difficulties wrapped up as the families' desire to stay with the patient during the final stage of her life."*

This assertion was reinforced from my field notes relating to a period of observation when I noted that one family declined to have their relative transferred to ICU. They stated that this was because they wished to continue to provide care for their relative (that would have been provided by nurses in ICU) but the doctor believed that the real reason was primarily financial. This was confirmed by a conversation between the relatives that I observed. As a result of this perceived hiding trust was eroded.

- o Hiding information from older patients

Hiding bad news from their older relative was the most important and most prevalent of permanent hiding demonstrated by family carers, often in collusion

with medical personnel. Carers often went to considerable efforts not to let their relative know of a poor prognosis or of the extent of the risks or costs involved in certain treatment options. This excluded them entirely from having any role to play in these often highly important decisions. Conversely decisions that involved little or no risk, such as diet or physical exercise were far more likely to include the older person.

It was clear that carers would selectively involve the older patient in decision-making based on the nature of the decision to be made and the extent to which it might compromise their '*peace of mind*'. Whilst ultimately well meaning such behaviour could also be viewed as being rather paternalistic.

Carers had different strategies to achieve their aim of hiding negative information. For example, in order to keep information private, they would talk about the negative information outside the patient's room rather than in front of them; or they might try to downplay (or sometimes even deny) the seriousness of patient's condition by telling a 'white lie'. A daughter described her experience of hiding bad news from her father:

> *Carer(5)13: "I will tell my father some information about his condition…I said 'daddy, you still have a little inflammation in your lung, and we will go back home as soon as you get recovered'…I have a principle which is that I only tell him the good news, but don't tell him the bad news. That is to say, I don't tell him all sorts of information, but only tell him positive information, but keep negative information secret."*

In addition to hiding potentially bad news about prognosis carers would usually hide the full economic costs of treatment, especially if this went beyond their insurance cover, as shown below:

> *Carer(20)5: "My husband has asked me a few times how much the hospital stay costs, and how much money we have to spend on his treatment. I said to him that he didn't need to worry or think about the cost, and the only thing he needed to do was to follow doctor's advice in order to receive effective treatment and make a good recovery. I told him that where there is life, there is hope. Life is definitely more important than money, because if we have a life, we*

can make money, but without life there is no hope for money. And at least his health insurance could cover part of his treatment cost, so he wouldn't have to spend lots of money on his treatment."

- Professionals' permanent hiding behaviour

Permanent hiding was commonly used by health professionals (as noted above often in conjunction with carers) and typically involved either downplaying or keeping bad news about the patient's poor prognosis. The rationale was usually to maintain a patients' 'peace of mind' in the belief that a happy mood leads to quick recovery. Consequently, considerable information was kept from patients. For example, if the patient had a major stroke, his or her doctor would decide to hide the seriousness of her condition. They might either downplay or partially conceal the truth by telling the patient that he or she only had a minor problem, or talk about his or her severe or life-threatening condition with carers or other colleagues outside the patient's room or in the doctors' office rather than in front of the patient. As a result, the patient was not in control of the information they received and could not make an informed decision. Indeed, they were often not involved in making major decisions at all.

However, doctors were more open with patients when the decision was about a minor problem, and allowed patients to make decisions on their own.

A doctor described very clearly his reluctance to tell patients bad news in order to potentially promote harmony. His deliberate 'hiding' strategy and the conditions under which 'hiding' would be practiced were reinforced:

> *Doctor15(2): "If the patient is in a serious or critical situation or has a very poor prognosis, I will tell the carer about his or her situation in order not to increase the patient's concern or psychological pressure, which may further influence his or her recovery. Of course when the patient doesn't have a normal consciousness level, I will also tell the carer about the patient's condition. Except for the above-mentioned circumstances, I may tell the patient or carer information about the patient's disease.*

> *Generally speaking, when the patient has a minor problem, is in a stable condition, or has a positive prognosis, we may talk to the*

patient and/or carer about treatment either at the patient's bedside or doctor's office. But if the patient is in a serious or life-threatening condition, or has a poor prognosis, we will only talk to carers about the patient's treatment, possible outcomes and prognosis. But we will not have this discussion in front of the patient, but in the doctor's office or outside the patient's room, in order to avoid the patient from knowing the bad news or negative information."

Some practitioners were more open about the limited information that they provided, but this could effectively silence the patient's voice:

Doctor(6)8: "When I went to the ward and wanted to talk with carers about a patient's condition, I only saw the patient lying in the bed, then I asked the patient where his carers were. He told me that the carers were not in the hospital at that time, so I asked him to let his carers come to my office afterwards.

The patient asked me why, I said that I needed to talk to them about his disease condition. Then he said 'please tell me about my disease condition.' I said 'let me tell you, you have the right to be informed, but not the right to be fully informed. For something that you should be informed, I must let you know; but I must tell your carers about the information which shouldn't be given to you'. After I said this to him, he no longer asked me for information again."

The other main reason doctors used hiding was to ensure a harmonious relationship with family carers and avoid possible conflicts with them. Patients' negative emotional reactions and other potentially negative consequences following the disclosure of the truth could make families very unhappy with doctors' performance and might trigger serious conflicts between families and doctors. This was illustrated by the following transcripts from the interview with a female doctor:

Doctor(6)7: "We will talk to patients about certain issues, such as how to carry out stroke prevention…but we can't tell patients about poor outcome or prognosis since the patient will be severely frightened if he knows about that…for negative information or something harmful to his emotional or psychological condition, we totally don't tell patients about it. Otherwise, if the patient becomes

upset or has other emotional problems after we tell the patient that negative information, the carer will complain to us, and conflicts will occur between both of us."

Doctor(11)10: "In China, in this country, I think we should provide negative information such as poor condition, diagnosis and prognosis to carers. For example, in the current hospital, generally we will provide all this information to family carers. I know that there were situations in which the doctor told the patient such information and made the patient very panic, then the carers went to criticise the doctor, how come you tell the bad news to our relative, how come you tell him the truth! So in China, the negative information should be provided to carers and allow them to have a full understanding about the patient's poor condition or situation, and make decision for patient. In China basically we don't let patients know the bad news."

Tailoring to hide

This behaviour was generally used by professionals who would selectively 'tailor' information in order to hide certain aspects or facts about a particular choice from patients and carers. Their willingness to provide detailed and clear information to patients and carers could be influenced by a number of factors such as the perceived trustworthiness of carers or patients, their own preference or desire for decisions, or the expected outcome or consequence of different choices. As a result of *'tailoring to hide'*, patients and/or carers still could not always make a fully informed choice.

- Tailoring to hide based on perceived trustworthiness of patients/carers

Doctors would selectively tailor information based on the perceived trustworthiness of carers or patients, in other words, they might either exaggerate or downplay the risks associated with a particular decision.

For example, sometimes, if doctors did not think that carers were trustworthy, they might talk in great detail about the risks associated with a radical or invasive treatment but downplay its effectiveness. At the same time, they would give more information about a conservative treatment which was usually safe but perhaps less

effective in resolving the patient's health problem. As a result, carers were more likely to choose the conservative or safer treatment.

On the contrary, if they felt that carers were trustworthy, doctors gave more information about the effectiveness of radical or invasive treatment and downplayed its potential risks. At the same time they gave less information about the conservative treatment.

Through this 'tailoring' process, doctors aimed to maintain harmony between themselves and carers as well as patients, and prevent possible negative consequences such as patients' poor outcomes, family complaints, or conflicts or tensions between themselves and patients and carers:

> *Doctor(10)11: "If I don't trust patients and carers, if I think that they are not trustable…when I communicate with carers, I may be more careful to give more detailed information about risk…because I feel that they don't trust me and so I also don't trust them."*

• Tailoring to hide based on professionals' preference for a particular choice

Another situation in which doctors selectively tailored information was when they had a preference for a particular decision. Here doctors might provide information that favoured their preferred treatment, whist downplaying alternatives. A doctor described how she used such tailoring behaviour when making decisions with patients:

> *Doctor(1)13: "If I prefer to provide more active treatment, I will talk to patients based on this preference…I may talk to patients about the advantages of the treatment, emphasise the strength of the treatment. I may also talk about the side-effects, but not describe the side-effect as being very serious…I will mainly focus on or emphasise the benefits to be gained from the treatment…If I intend to use conservative treatment, I will put more emphasis on the risks associated with the active treatment."*

- Tailoring to hide based on the anticipated outcome of choices

Professionals would selectively tailor information based on the anticipated outcome or consequence of different choices. This was quite common, especially when decisions regarding thrombolytic treatment needed to be made. Here there was evidence that practitioners, both doctors and nurses, tailored the information given to carers or sometimes patients, depending on what they thought that the clinical outcome was likely to be:

> *Nurse(16)4: "Sometimes, a nurse may say to a patient that 'you know the patient X, he has got the similar health problem, and has good effect after thrombolytic treatment'. Of course, the nurse must have understood the current patient's disease condition very well, had sufficient specialised knowledge, and made an estimation of the effect on the patient of thrombolytic treatment. She feels that the patient will have a good effect after thrombolytic treatment, and so she uses a positive language to facilitate the patient to accept the treatment.*
>
> *However, based on the patient's condition and my clinical experiences, and the patient's results from related tests, examinations, and MRI, you make a judgement after a comprehensive analysis, you feel that the patient will not have a good effect after thrombolytic treatment, then you may not have a very positive attitude towards the treatment when talking to patients or their carers.*
>
> *On the other hand, although the patient may have a good effect after thrombolytic treatment, if the patient has very high risks or may encounter a life-threatening situation during thrombolytic treatment, we will also pay greater attention to and be careful of our language when talking to carers…we need to tell them both the pros and cons of the treatment…however if we think that finally the patient may have a better outcome and prognosis after treatment, we will facilitate them to accept the treatment, we will tell them more effective examples."*

Doctor(1)13: "If I intend to use conservative treatment, I will put more emphasis on the risks associated with the radical or invasive treatment, because based on my experiences, or the current treatment protocol…although the patient is able to receive the radical or invasive treatment, the risks will far outweigh the benefits. Or sometimes for some patients the benefits may outweigh the risks. Based on my experiences…I will be able to know what kind of patients can get good treatment effect and what kind of patients can have poor treatment effect."

Doctor(12)4: "When there is a need to make treatment decisions, I will talk to patients or carers with a kind of preference or intention in my mind. For example, if I think that this patient is really suitable for the thrombolytic treatment, or the anticoagulant therapy, I expect that the patient will have a good treatment effect, then when I talk to the carer about this treatment, I will definitely suggest that the patient receives this treatment, and recommend this treatment to the carer. So I will tell the carer that the patient has treatment indications but without any contra-indications. But after all, the thrombolytic treatment involves risks, so I also will tell the carer about the risks involved, and then leave the final decision up to the carer."

Again, in the above examples, the doctor and the nurse gave more information about a choice which was more likely to result in a positive outcome or prognosis, and downplayed or hid information about a less effective choice. Their underlying motivation was to avoid potential problems, poor treatment effects, and conflicts, and to maintain harmony in professional-patient-carer relationships.

The above section has explored the various dimensions of hiding behaviours and their relationship to the other core category '*Keeping the peace'*. Attention is now turned to the second basic social process in '*Making decisions'* that of '*seeking'*.

<div align="center">Seeking</div>

Seeking processes were mainly used by patients, carers and professionals for a number of reasons including: to obtain initial medical help; to try to find a hospital; to actively search for information about their illness and so on. Under the category

of seeking, three sub-categories were identified: (1) searching; (2) watching/comparing; and (3) checking.

Searching

This involved active and overt attempts to obtain information from a variety of sources in order to help in the process of decision-making. Searching was used by all parties at differing stages.

- Patients' and carers' searching behaviours

Searching for initial medical help was usually the first phase of 'searching', and involved recognition that something potentially serious was wrong:

> Patient(2)1: "I suddenly got sick at night…my wife immediately called 120 for ambulance service, and the staff quickly sent me to the hospital."

> Carer(15)1: "When we came back and found that our mother lay on the floor…we immediately dialed 120 to call an ambulance…and sent her here for treatment."

At this point, if time allowed, patients and carers often 'searched' for the hospital which they perceived to be the most ideal and appropriate one. As noted earlier, this was often influenced by a range of factors such as proximity and convenience, local reputation, prior experience of a certain facility or the perceived nature of the problem. For example, a daughter reported that,

> Carer(20)1: "We sent the patient to the county hospital…her condition didn't improve…so we accepted the doctor's suggestion and transferred her to the specialised hospital…but since she also had other problems…so we transferred her to the general hospital…there was no bed available in that hospital…finally we transferred her to the current department."

Other searching behaviours used by patients and carers were largely related to proactively searching for health-related information by:

o Using mass media, for example, reading books, newspapers, magazines which talked about health related knowledge; watching TV programmes and searching on the Internet. A male patient and his son described their searching behaviours:

Patient(7)3: "When the doctor prescribes medication…I often read some books in order to understand the treatment effects of the medication."

Carer(6)5: "Caring for a patient is an important research topic…if I've got questions, I will immediately search the Internet to quickly get related information."

o Accessing staff expertise or others forms of technical knowledge, for example: asking the doctor to give them the IV medication instructions to read; listening to doctors' discussions or explanations during ward rounds; asking doctors and nurses to explain their disease, medication and treatment; asking doctors and nurses for dietary advice, discharge and follow-up instructions and so on.

Doctor(3)35: "When making decisions on diet, patients or carers will ask me what food the patient should eat during the hospitalisation…they consult doctors for advice…some patients also ask me 'doctor, can I get out of bed now? Is that okay if I have a walk?'"

Carer(6)9: "I ask medical students questions related to common medical knowledge…about brain cell disease and the current situation or progress about its treatment or management strategies."
(a son)

o Consulting other patients who had the same disease, or had been through the same procedures/treatments:

Doctor(5)2: "Patients or carers may consult other people, for example, ask other patients with stroke…about how to make decisions…or consult other friends with a similar disease…about their experiences of receiving treatment".

o Using patients' or carers' networks and personal contacts, for example consulting colleagues or friends who had suffered from a similar condition, or had looked after patients with similar health problems, or were health professionals:

Doctor(5)2: "Patients or carers may consult other relatives or friends who are health professionals…to help with their decision-making."

Doctor(4)3: "Sometimes patients or carers don't have clear understanding about the disease, so they need to have some relevant information in order to be able to make decisions. Therefore patients, or mainly family carers will consult other people. For example, they may ask or try to get the information from their own personal contacts, personal network, or friends, especially those working in hospital which can be either the current hospital or other hospitals. Patients and carers will get information from these people and based on which then make their decisions."

Carer(10)5: "My colleague once had taken care of her mother for 7 years, and her younger sister is a head nurse…since my older father needs lots of care, so I always ask both of them questions and learn from them about how to look after an older patient." (a daughter)

o Attending training, for example, going to the University for older citizens and taking courses on self-management of chronic conditions to learn strategies to maintain a healthy life style.

Patient(9)6: "I try to well manage my own disease and keep a healthy lifestyle…I gained the knowledge about managing diabetes when taking courses at the university for senior citizens…I think it is really worth spending a couple of years taking courses and learning knowledge in that university." (a male patient)

- Professionals' searching behaviours

Health professionals' searching behaviours were primarily concerned with their attempts to get information about patients' health conditions from either patients or carers. However, professionals also recognised and searched for patients' and carers' expert knowledge, although this happened in relatively fewer cases. For example, a doctor spoke highly of the value of knowing about a patient's previous examinations or treatments:

> *Doctor(12)8: "In terms of valuable information given to us by patients or carers, for example, when I ask them about the experience of receiving treatment or examination, they may tell us that their patient was once given a certain type of examination in a certain hospital, but we don't have this one in our department, so we know that the colleagues in another hospital use this examination to diagnose the patients' problems. This type of information is very useful, and I can get it through asking patients or carers during either their hospitalisation or their OPD follow up.*
>
> *Some patients or carers may also let you know where they got treatment, what treatment had been given to them, the examination that they had received, and the advice that they had been offered in other hospitals, so by asking your patients and their carers, you will be able to know how your colleagues in other hospitals give treatment and manage patients' disease, and understand their skills or techniques for dealing with patients' health problems. This valuable information can help you understand and keep up-to-date with scientific developments in medical fields."*

She gave another interesting example of the importance of knowing about patient-related information via asking carers. In this case, she deliberately tried to understand the likely personal or psychological response of the patient to bad news and to gauge the families' preferences for whether or not to disclose the truth to patients. Based on the above information she then decided the appropriate way in which to communicate with her patients. This doctor also appreciated family members' expertise based on their long term familiarity with the patient:

Doctor(12)9: "Since generally speaking, carers clearly understand about the patient's personality and potential emotional reaction after knowing the truth regarding their condition or poor diagnosis, so in order to know this information, I will ask carers about it and very much respect their decisions as to whether or not to tell their patient the truth.

Some carers may be afraid that the bad mood caused by knowing bad news may have a negative influence on the patient's recovery, in these circumstances, I think I should respect carers' suggestions and therefore, I will not tell patient the true information regarding their poor condition.

When a patient comes to see you for treatment, since you don't know him or her before, so it will be very difficult for you to have a thorough understanding of everything about the patient, therefore you need to indirectly gain this understanding or information from carers' introduction or description about the patient. So I think the mutual communication between carers and us is very important."

Similar searching behaviours were used by nurses, who recognised family carers' practical skills in caring for the patient or knowledge of traditional healing approaches. A nurse described her perspective by saying,

Nurse(21)17: "Nurses may seek information related to nursing care or traditional medicine from carers, such as how to effectively provide tube feeding to ensure the patient's regular bowel movement, or how to prevent patient's constipation by giving them sesame seed oil to drink. Nurses may further pass this information onto other patients or carers with similar information needs."

Watching/comparing

Another approach to seeking was the less overt practice of 'watching/comparing that was used mainly by patients and carers. This involved closely observing other peoples' behaviours as well as the environment around them. A closely related process was that of 'comparing' their treatment/progress with that of other patients in order to make judgements about their own care. For example, a carer watched

what happened to her patient and to other patients and made detailed comparisons to try and understand similarities and differences:

> *Carer(10)8: "I find that the Deproteinised Calf Blood Injection used by other patients is made by the pharmaceutical company in Haerbin, but the one used by my father is made by the pharmaceutical company in Shenyang. So I very carefully compare the descriptions and instructions about the medication on their packaging, in order to identify the differences...I find that the Deproteinised Calf Blood Injection used by my father is much more suitable for his particular condition." (a daughter)*

Patients reported that they observed other patients' behaviours carefully in order to inform their own decisions. For example, they closely watched fellow patients' behaviours, e.g. hiding disease information from doctors, leaving hospital early, or being unwilling to participate in physical activities during hospitalisation, and made judgements on the appropriateness of such behaviours. This often shaped their decisions or behaviours. For example, they might decide to tell a doctor their full disease history or to stay longer in hospital.

In order to inform their own decision-making, family carers also often actively used watching and comparing strategies. For example, the daughter of a female patient explained how she carefully watched other patients with a similar disease or care needs, the decisions their carers made and outcomes or consequences of their decisions. This influenced her decisions as illustrated below:

> *Carer21(3): "When the doctor asked us if we would like to choose to give the patient gastric tube feeding, we decided to follow the doctor's advice. Because according to the doctor, since the patient can't eat and drink normally, so she very much needs to have a gastric tube inserted, through which we can provide various types of nutritional food or diet. Otherwise, she will not be able to get enough nutrition and make a good and quick recovery. So we decided to accept the doctor's advice on tube feeding.*
>
> *I noticed that in our room there was a female patient who also needed tube feeding. But her daughter strongly disagreed with the doctor and refused to give her mother tube feeding, because she*

believed that giving tube feeding could increase patient suffering, and cause great discomforts or even pain to the patient. But afterwards, the patient's nutritional status was increasingly getting worse and worse, and then she couldn't even sit up but had to lie down in her bed all the time. Finally, her daughter had to accept the doctor's advice and choose to give her mother tube feeding.

So, based on my observation, I believe that if the patient can't eat and drink normally, he or she must be given tube feeding, otherwise, he or she will not be able to get enough nutrition to improve their condition, and to maintain good nutritional status. So I think giving nutrition through tube feeding is very important and helpful to the patient's recovery." (a daughter)

In addition patients and carers watched and compared health professionals' behaviours and used this to inform their decisions:

Patient(15)9: "Before I go to bed, sometimes I walk a little while outside my room, I notice that, at a few minutes after 9:00 pm, when nurses find that there are few patients or carers in the corridor, they will turn off the lights; but on the contrary, if there is still somebody in the corridor, they will turn off the lights a bit later, and this makes it very convenient for patients and carers to finish what they are doing at that time. And meanwhile, nurses also remind patients to go to bed by turning off the lights rather than by criticising or blaming them.

I think they do a very good job, and their working style is very good…I am a very conscientious person, and so I can notice that their management is very good by close and careful observation." (a female patient)

Carer(18)13: "I find that there is a very good atmosphere and environment in this hospital…but there is not a good and harmonious atmosphere and well organised environment in the general hospital, which like this current one is also a level 3 hospital in our city. I've been to that hospital a few times and I always found that there were conflicts happening over

there…however, similar to that hospital, there are also lots of patients coming here for treatment, but we never think that there is a messy or disordered environment here." (a son-in-law)

Checking

Another form of seeking behaviour was 'checking'. Patients and carers used checking processes to verify or confirm the truth, accuracy or correctness of the information given to them by professionals (e.g. doctors) by, for example, consulting another source or authority. This usually happened if they did not fully trust the original source. A wide range of approaches were used for checking including: asking nurses; searching on the Internet; directly asking the doctor questions; asking other doctors for advice; asking patients with a similar condition; and consulting their wider social network e.g. relatives or friends or neighbours who were health professionals. This was captured by a nurse as follows:

> *Nurse(22)3: "When patients don't trust doctors, they will be suspicious about doctors' advice or explanations. Some patients or their carers even go to other hospitals to check with doctors over there about the advice given by their current doctors, such as the treatment plan of their disease. They need to go to several other hospitals to check whether their doctors give correct advice."*

Some patients and carers did not blindly trust doctors and their treatment advice, and so would check the information or explanations given by doctors in many different ways before they made their final choice. In the following example, the male participant described his experience of double checking oral medication before taking it, reflecting a careful and conscientious self-management strategy, which was attributed to his working experience.

> *Patient(1)9: "I am a very conscientious person. I am very careful about taking any medications. But I still had the experiences in which I took wrong medications for about one week…Since I had these experiences, so I am very careful with taking my medications. After the doctor prescribes medications for me, when the nurse distributes medications, I check them. Each time before I take my medications, I check them once again. I think this habit may be also related to my working at a bank…so I double check my medications*

before taking them." (a male patient)

This checking strategy could help alleviate a patient's and their families' uncertainty and give them more confidence in their choice. This is apparent in the following description:

> *Patient(10)9: "I felt uncomfortable during the process of receiving the therapy, but felt much better after I finished the procedure. I once asked other patients who had received the same therapy, and knew that different people might have different experiences and feelings when receiving the therapy." (a male patient)*

<div align="center">Sharing</div>

The main purpose of overt sharing behaviours among patients, carers and professionals was to give information or experiences to others so that they might benefit. Under the category of sharing, four sub-categories were identified: (1) informing; (2) advising; (3) exchanging; and (4) tailoring to explain.

Informing

Informing processes were actively and widely used by patients, carers and health professionals to give or provide information to others so as to increase their awareness.

- Patients' and carers' informing behaviour

Informing manifested itself in various forms and at differing points. Often the earliest example occurred immediately following the recognition of stroke symptoms, or when patients realised that something was wrong. For example, patients would usually inform the person they lived with in order to initiate the help seeking process. However, as noted earlier sometimes this informing was delayed if it was thought that it would reduce carers' peace of mind. Two participants explained the importance of informing behaviours in avoiding possible delays in seeking medical help:

> *Patient(9)2: "The time when I got a stroke was just around 8 or 9.00 in the evening, immediately after I found that I had got sick, I told*

my child about my problem…she took me here to get treatment…if I didn't tell my child about my disease until the next morning, it would be too late for getting treatment." (a male patient)

Patient(6)3: "My children don't live with us. After my wife called them and told them that I went to hospital for treatment, they directly came here by car, so very fast, and they arrived here before 3.00 am." (a male patient)

Both patients and their family members informed doctors of patients' past disease and treatment history, current condition, treatment effect or outcome, or progress of recovery. Based on the information provided, doctors would be better able to make an accurate diagnosis and give effective treatment advice to allow carers or patients to make a choice. Patients and carers also let doctors know their concerns. For example, a patient showed his MRI scan from another hospital to his current doctor, and told the doctor everything about his disease condition and history.

Sometimes, family carers or patients offered health-related information, knowledge or their own experiences to fellow patients and their carers in the same room or ward. For example, they might tell other people what they knew about the disease, treatment or examination, their understanding about the hospital, staff members or quality of service, as well as their own experiences of going through similar examinations or treatments.

- Professionals' informing behaviours

Professionals' informing mainly involved providing patients, or more often carers with information about their disease, examination, treatment and care that was considered important for decision-making. This could take a variety of forms. Two members of staff expressed their experience of face to face interaction with patients and carers as follows:

Doctor(10)2: "We (doctors) will provide some information for patients and carers to take into consideration…will introduce information about pros and cons of examination or treatment to them, provide them this basic information which they need to know about before making choices."

Doctor(11)3: "I will very clearly provide information about pros and cons of each alternative choice to carers or patients, after all, they are not health professionals, and haven't had medical education. But I don't have the right to make decisions for them, what I can do is to tell them the pros and cons of treatment and examination, and then allow them to make decisions. For example, if they choose to accept a certain treatment, we will try our best to give that treatment to the patient; if they decide to refuse a certain treatment, we will not provide that treatment to the patient."

Nurse (16)1: "from the perspectives of nurses…we need to enable the carers to understand the surrounding environment and to get to know the people around, and then provide relevant information and introduction according to patients' disease and health condition, for example, the prognosis of their disease and treatment. In addition, we will also give a related introduction based on the doctors' diagnosis and treatment plan…tell patients and carers the important things to which they need to pay great attention during their hospitalisation. These are the main focus of our work."

The provision of high quality information was greatly appreciated by patients and carers. In addition to face to face contact they valued health education information from posters on walls or notice boards (e.g. knowledge about disease and treatment, or flow charts on procedures of admission and discharge) that also allowed them to make better informed decisions. A more proactive form of informing was advising.

Advising

Advising, as the name suggests, went beyond the simple provision of information to include a 'steer' as to which way a decision should go. This process was widely used by many health professionals who would either openly advise patients or carers on what to do or else actively promote a certain course of action. However, in the majority of cases the final decision still rested with the family.

A similar process could occur between patients and carers within the same family or those sharing the same room or ward. For example, family members might give health related advice to their patient, or advise other family members about how to make a choice for the patient. As mentioned earlier, children-in-laws were typically

perceived as advice providers but were likely to leave decisions up to the patient's spouse or children.

Some patients and their carers were enthusiastic in advising others. For example, a male patient described his experience of advising a fellow patient in the same room to stay in hospital until his health problem was accurately diagnosed:

> *Patient(5)12: "I said to the patient that he shouldn't be anxious to go back home, but rather, he should stay in the hospital for one more day…I mean, he shouldn't make the decision about whether to be discharged from the hospital until he received the results of his cervical vertebra examination and understood about his diagnosis…but he didn't follow my advice, and insisted that he should be discharged…and left the hospital."*

Professionals also reported that patients/carers sharing the same room might talk to each other about treatment or other care interventions and give advice on these issues, and that this potentially had great impact on the choices they made. A physiotherapist shared his experiences:

> *Physiotherapist23(3): "Since there are generally three beds in one room, so information given by patients or carers sharing the same room will have an impact on their decisions. For example, patients or carers sharing the same room may not have much understanding about medical knowledge, but they may give advice to others out of kindness. But since they don't have enough medical knowledge, they only have a very superficial understanding about medicine, so sometimes they may suggest to other patients or carers that there is no need to give rehabilitation therapy to patients.*

> *Especially when there is a newly admitted patient, he or she will believe that information or advice given by the other two patients, who have stayed longer in the hospital, must be correct, so that's why I say that information from fellow patients or carers may have a negative impact on patients' or carers' decision-making.*

> *Of course, there are also positive influences, information from fellow patients or carers may have both positive and negative influences. I*

also encountered a situation in which a patient received rehabilitation yesterday and had a good effect, so today another patient sharing the same room knew about this and decided that he also needed to receive rehabilitation.

Patients and carers sharing the same room often chat with each other during their hospital stay about issues such as patient condition or treatment...they may not necessarily deliberately want to create a bad influence on other people's decisions, but since they don't know much about rehabilitation, so they may not think that rehabilitation is necessary, and so they may suggest other people not to give rehabilitation to patients."

Exchanging

Exchanging was an important form of sharing behaviour, and involved a more dynamic two-way communication between people. It was mainly used by patients and carers when they reciprocally exchanged information, ideas, views, or opinions with each other.

Exchanging and the watching/comparing process mentioned earlier were often closely related to each other. For example, patients and family members might use watching to observe other people's behaviours, use comparing process to identify the similarities or differences between things that happened to them and what happened to others, and use the exchanging process to actively share information with each other. Often patients sharing the same room would exchange their own experiences of disease or receiving treatment, examination, physical therapy, or TCM. Similarly, patients and family members would exchange their experiences with other patients and families on a whole range of issues such as their experiences of seeking timely medical help, the way in which they maintained a healthy life style, information about the hospital and the quality of its service, or their opinions on a particular staff member's performance.

Since there were three beds in most patient rooms and patients/carers often had little to do to fill the time so that the mutual exchange of information, experiences, ideas and opinions provided a common currency of exchange. This was facilitated by the fact that family members often stayed 24 hours a day for the whole hospital stay, allowing significant opportunities for exchange. Such exchanges could either

facilitate or inhibit the development of trust between patients, carers and professionals. For instance, good comments about a doctor (e.g. how effective the treatment was, or how good the doctor was) were likely to result in patients and carers trusting them. On the contrary, if patients and carers had received negative reports from other patients and carers this often had the opposite effect. As such these exchanges could exert a quite profound effect as it involved an exchange between equals, without the power imbalance that often existed between patients, carers and professionals.

Tailoring to explain

As noted earlier, tailoring behaviours involved altering or adapting information to meet a specific need or to suit a particular purpose, and was commonly used by all three groups of participants. One of their major motivations was to give explanations through clarifying or explaining the meaning of something or trying to make information plain and comprehensible. Tailoring to explain was mainly used by carers and professionals during the decision-making process.

- Carers' tailoring behaviour

Carers might use tailoring processes to explain a doctor's advice or treatment plan to other carers to help them make a decision. For example, when he explained doctors' treatment interventions to his father-in-law, a son-in-law of a female older patient deliberately made his words suitable for the level of understanding of his father-in-law. Therefore, although he did not make the ultimate decision the information he had provided played a large part. His father-in-law was satisfied with the important role played by his son-in-law in delivering and interpreting the information needed for his decision-making:

> *Carer(18)3: "In order to help my dad to make his decision, I will give him clear explanations, for example, the purpose of the treatment, why my mom needs this medication, what problem will be solved by receiving this treatment. Because sometimes, older people may not understand this information about the treatment or medication, so I need to very clearly explain all these issues to him, then it will be easy for him to make his own decisions." (a son-in-law)*

170

> *Carer(17)3: "I think compared with young people, we need to take more time to be able to understand some new knowledge or scientific knowledge, so I need to listen to his explanations, and then based on his explanations, I can make decisions." (a husband)*

Carers also used tailoring processes to explain the meaning of a doctor's advice or treatment plan to their patients in order to reduce their fears or concerns and help them to maintain a happy, peaceful and relaxed state of mind. A clear understanding about the purpose of treatment interventions could help the patient cooperate better with doctors during their hospital stay.

- Professionals' tailoring behaviour

Professionals would selectively tailor or explain information based on the perceived level of understanding of patients and carers. Doctors or nurses would present scientific information in an easy-to-understand way when they needed to explain complex issues to patients and carers. This is often key to patients and carers making an informed decision. A nurse described her experiences by saying,

> *Nurse(16)8: "Patients and carers feel that it's easier to communicate with nurses, because doctors sometimes use more professional terms, so it's very difficult for patients and carers to understand those terms…so they don't understand what doctors say to them, then nurses use very simple language which is very easy to understand to explain to them, so they can understand, like the purpose of taking a certain kind of medication, or the purpose of a certain treatment intervention, then they can quickly decide to accept the medication or the treatment."*

This suggested a complementary but slightly different role for nurses, who whilst supporting the doctors' role provided explanations to patients and carers in a way that matched their level of comprehension. The nurses' role in interpreting or translating information from doctors into a form that lay people were able to understand not only helped patients and carers successfully make informed decisions, but also helped to maintain a harmonious relationship between doctors, patients and families.

Often patients' and carers' experiences resonated with the data provided by staff. In the following example, a male patient described how his doctor gave him a vivid explanation about his disease and how he developed it by using a metaphor of how the deposits of coal soot were developed and formed on the wall of furnace chimney and obstructed the chimney and interfered with the smoke flow. Given the patient's age and lack of medical knowledge, his doctor made an attempt to help him understand the abstract and complex pathological mechanisms leading to the development of stroke by using a metaphor, which was more approachable and easier for him to understand.

> Patient6(2): "After I had a stroke, I came here to see a very senior doctor who was an expert. I asked him about my disease condition and how I developed this disease. He gave me the clear explanation by using a very vivid metaphor. He said 'let me give you an example, you see the furnace chimney, which is like your blood vessel. When you just start to use your new chimney, it functions very well and can vent gases or smoke very quickly and effectively. But after you have used it for a long period time, the chimney will develop deposits of coal soot which are formed on its walls. This is a characteristic problem of chimneys, and the deposits of this substance can obstruct the chimney and interfere with the smoke flow, very much like your disease problem'.
>
> He continued, 'that is to say, over time when you are getting older and older, some types of deposits begin to develop and accumulate in your blood vessels which then become narrow, then after a long time, the deposits can begin to obstruct and eventually completely block your blood vessels and destroy your blood flow and circulation. And at a point during the process of disease development, you may get sick and have a stroke'."

Tailoring behaviours motivated by other goals

Some tailoring behaviours were motivated by other goals. For example, patients or carers would sometimes tailor their words when talking to doctors if they disagreed with or questioned their advice. Their underlying goal was to initiate a conversation about a sensitive topic or area, carefully express their disagreement, and negotiate and reach a compromise with doctors whilst maintaining a harmonious relationship

and avoiding potential embarrassment or conflict. A male patient and the son of a female patient reported respectively how they used tailoring process when working with doctors. They said,

> *Patient(1)3: "If the doctor wants to change my medication, I will discuss with him whether I don't need to change my medication, because I don't want to change my medication, which is very effective for me to keep my blood sugar very stable…Yes, when I talk to my doctors, I use a tone of speech or a manner of expression which is very much like having a discussion with them."*

> *Carer(7)12: "When I need to raise questions or concerns to doctors…I always use a tone of speech or a manner of expression which is very much like having a discussion with them, or very much like learning knowledge from them."*

Often to enhance their perceived credibility patients and carers used quite professional language or academic terms when they communicated with health professionals. Examples included terms relating to their condition such as cerebral infarction, cerebral haemorrhage, brain cell disease, hypertension, rheumatoid disease, heart failure, chronic bronchitis, and chronic inflammation of respiratory tract, high cholesterol level, and sequelae, or to their treatments or examinations (e.g. Avalide tablet, Betaloc Zok tablet, Gliquidone tablet, Bayaspirin, Acarbose, Deproteinised Calf Blood Injection, Vinpocetine, percutaneous transluminal stenting, and cardiac angiography). Participants who used these academic terms tended to be patients and carers who had a long-term experience of managing their disease or taking care of patients, and those who considered themselves as 'co-experts'.

Their behaviours seemed to be another form of 'tailoring' aimed at establishing credibility, so as to convince the doctor that they were competent and worthy of receiving further information, thus trying to facilitate a more equal exchange of information between them, ultimately creating and maintaining a good and harmonious relationship between themselves and professionals during decision-making process.

However, their behaviours could have a negative effect, in that if the doctor believed that patients or carers understood academic language, when in fact they

did not, he or she might respond using the same language, and the patients and carers might not fully understand what they were being told. Therefore, this type of tailoring behaviour could jeopardise effective decision-making.

Having explored the dimensions of the two core categories attention is now turned to the dynamics between them.

The Dynamics between the Two Core Categories

The dynamic and reciprocal relationship between the two core categories and their various subcategories and the part played by the range of other factors in the decision-making process are illustrated below in Diagram 6.3 which brings together the main elements of the theory developed in this study.

Diagram 6.3 Dynamics between the Two Core Categories and Other Factors
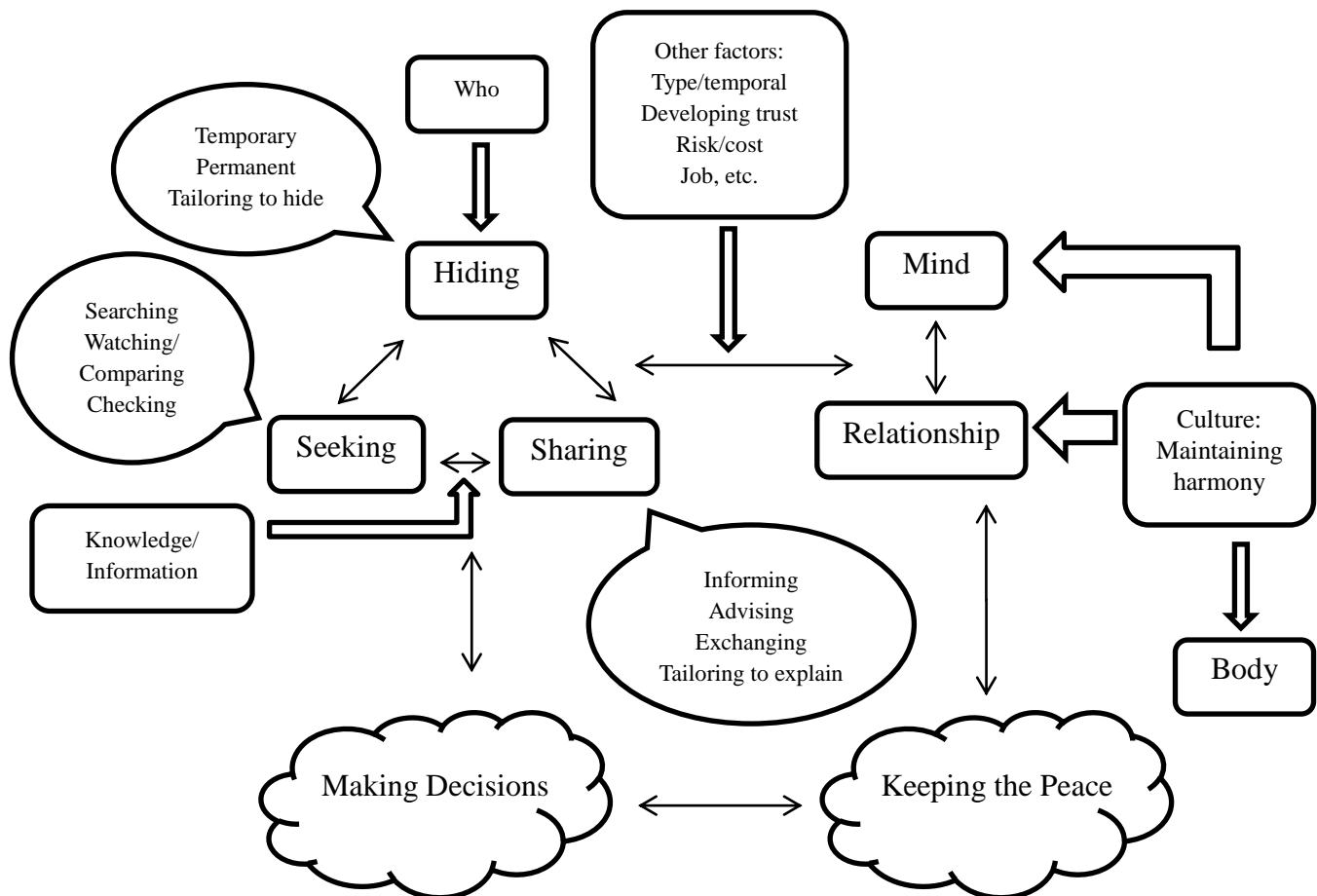
Making decisions was the main activity shaping the nature of the patient/carer journey following stroke. As already noted the single most influential factor was the desire to 'keep the peace' underlying which was the traditional Chinese cultural value of 'maintaining harmony'. 'Keeping the peace' took a variety of forms but was primarily concerned with maintaining 'peace of mind' for the patient (which was strongly linked to a better outcome) and maintaining harmony in relationships. The need to keep the peace had a profound effect on the nature of the focus of the second core category, 'making decisions'.

In order to effectively make decisions patients, carers and professionals used a range of key social processes which were grouped into three major categories named hiding, seeking and sharing. Subcategories of temporary hiding, permanent hiding, and tailoring to hide formed the hiding processes. Searching, watching/comparing and checking processes fell under the category of seeking. The subcategories of sharing process included informing, advising, exchanging and tailoring to explain.

One of the main consequences of the above desire to 'keep the peace' was that the older person was often effectively precluded from a full and active part in decision-making, usually for an essentially altruistic reason, in order that they were protected form information that might diminish their 'peace of mind'. Consequently the findings suggested the central theme of Chinese traditional culture, the idea of 'maintaining harmony', was the most important overall background factor influencing the dynamics between the two core categories.

For some groups especially those from the Hui minority, harmony had an extra dimension that related to 'maintaining the whole body'. This often resulted in families rejecting certain interventions, especially in instances when death seemed likely.

In addition to the main dynamics between the two core categories, other important factors were involved and played a key role in participants' decision-making processes. For example, hiding was central to the goal of keeping the peace, but also largely determined who was involved in decision-making activities. The hiding of several types of information from the older person often effectively precluded them from an active role.

Similarly, seeking and sharing behaviours were closely associated with the goal of keeping the peace and participants tried to both keep the peace and make decisions through seeking and sharing information with each other. However, unlike hiding, seeking and sharing processes influenced how knowledge and information was used by patients, carers and professionals. Also, as noted, several other factors influenced decision-making activities including the types of decisions to be made, when decisions were made and a variety of issues related to treatment (risk, cost), patients/carers (age, gender, education level, job), professionals (seniority) and the hospital environment. Examples of the type and range of interactions is provided below using a variety of case studies from the data.

Scenarios Illustrating the Dynamics Occurring between the Two Core Categories and Other Factors

In this section, examples of scenarios illustrating the active dynamics between the two core categories of making decisions and keeping the peace are presented, highlighting the key role of 'keeping the peace'. Six scenarios are presented that consider keeping the patient's peace of mind and eight that relate to keeping the peace in relationships. These are illustrated in the figures below.

Diagram 6.4 Key Processes Aiming at Keeping the Peace of Mind
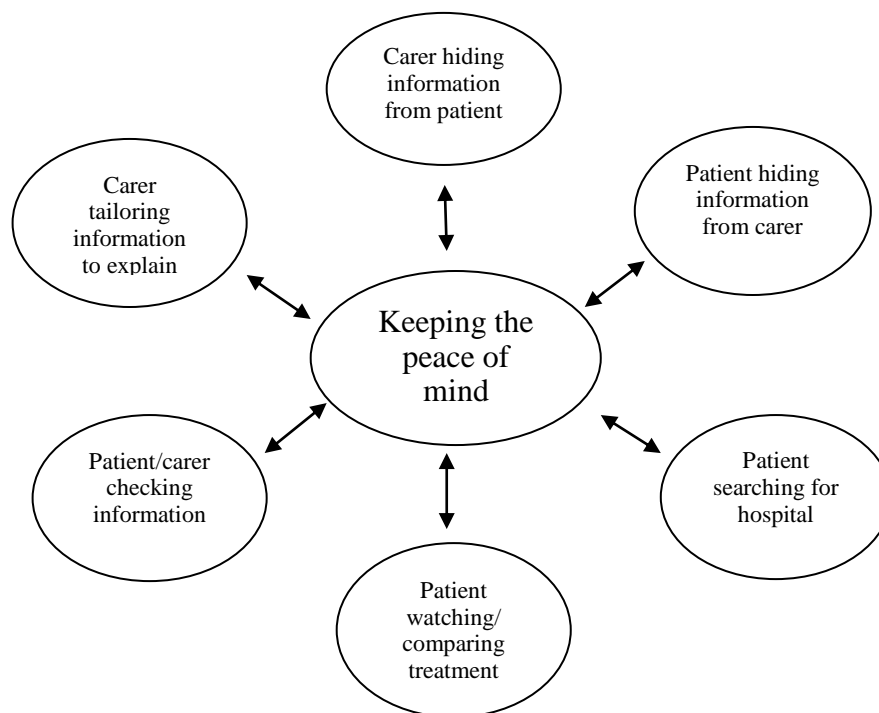
Diagram 6.5 Key Processes Aiming at Keeping the Peace in Relationships

Staff hiding information from patient

Staff tailoring information to patient/carer to hide

Staff disclosing information to patient

Fellow patients/carers exchanging information

Keeping the peace in relationships

Patient hiding preference from staff

Carer advising fellow patients/carers

Patient/carer informing staff

Carer searching for advice from siblings
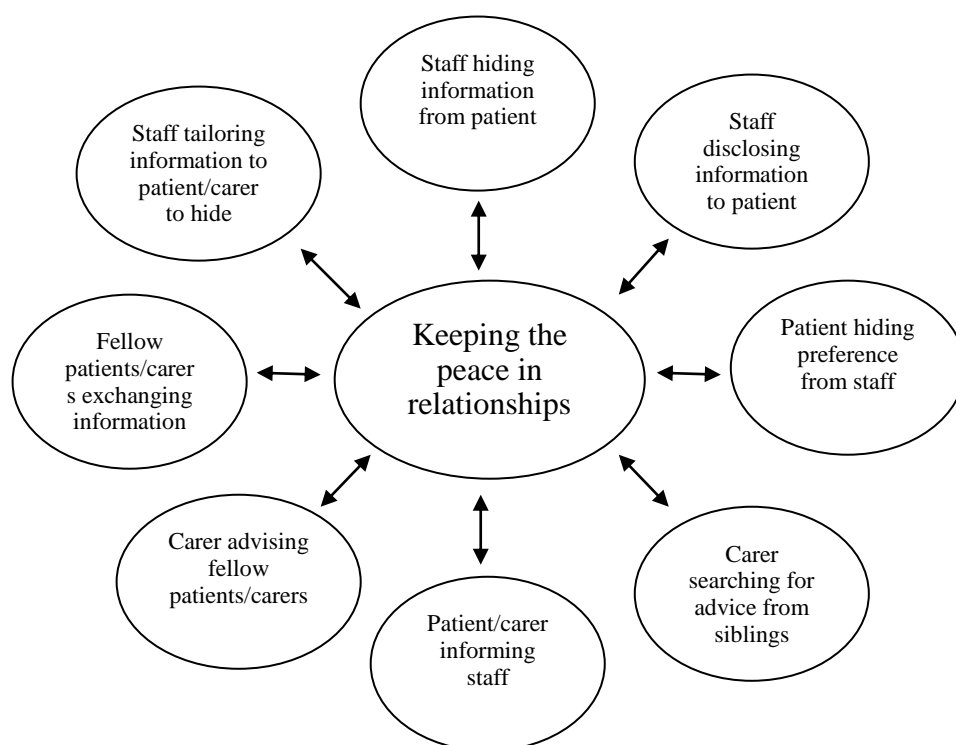
Key Social Processes Aimed at Keeping Peace of Mind

Carer hiding information from the patient

Preventing older patients from knowing negative information was considered most important by family carers when they made decisions. As a result, family carers often tried not to disclose bad news or unfavourable information to patients, such as issues concerning their critical condition and poor diagnosis, high risk or high cost treatments. For example, a 52 year old daughter of a female patient hid the true information about her mother's critical condition and risky treatment:

> *Carer(19)2: "We don't fully tell our patient the whole truth about her condition...we only told her that she just had a fall, but we didn't tell her the truth about her critical and very dangerous condition, especially what happened after she was admitted. Anyway, afterwards, she seemed to just know, 'well, I had a fall, and now my condition becomes much better, and my life has been saved'.*

We deliberately want to keep her from knowing the true information about her condition…Again for example, we didn't tell her about the things which we talked about during our discussion with the neurosurgeon, because we thought that there was no need to let her know those things about the surgery, like the risks associated, otherwise, this information might increase her concern or mental pressure and is really not good for her recovery, so we only told her that she just had a small problem rather than a big one, and that she would make good recovery after she received treatment here in the hospital.

We don't dare to let our patient know the truth about her condition and treatment, so generally speaking, we always talk about these sorts of things outside her room, rather than in front of her, otherwise, if she knows the truth, she may become more concerned about her condition and health…it will be very bad for her…it may increase her concern about her health or mental pressure, and therefore may exert a bad influence on her recovery…our basic principle is that we only let her know good news."

In this scenario, the daughter downplayed the seriousness of her mother's stroke and kept secret the information about potential surgery involving risks. The essential purpose of the daughter's hiding behaviour was to keep her mother's peace of mind. In other words, she tried to minimise any potential concerns, fears or anxiety which were considered detrimental to her recovery, and to keep her in a happy mood and to facilitate her good recovery.

In terms of a temporal dimension, this type of hiding behaviour was likely to happen at the early stage of the patient's hospital stay and then last throughout the entire patient journey, indicating the permanent nature of the behaviour and its effect on decision-making process.

Patient hiding information from carer

Patients were found to temporarily hide negative information from family carers. For example, a 61 year old male patient hid information about his stroke and hospitalisation from his wife, and did not disclose the news until he was

successfully admitted to the hospital and had received timely initial treatment.

> *Patient(17)6: "From the very beginning, I mean, the first day I got sick, I decided to keep this news secret from my wife, because she, like most women, is always likely to feel anxiety or to have fears when hearing about bad news. And because at that time when I got sick, I was working in Beijing, so it was easy for me to keep it secret from my wife.*
>
> *At the onset of my stroke, I didn't realise or have a clear understanding about the seriousness of my disease, that is to say, I didn't realise that I even needed to be admitted to hospital to receive treatment for my problem. The doctor suggested that I needed to be admitted to hospital, but since there was no bed available at that moment, so I had to stay at A&E to temporarily receive treatment and meanwhile wait for a bed. After one day of treatment at A&E, there was still no bed available. So I decided to come back to Tianjin for treatment. I was directly transferred to the current hospital, and was admitted to this department.*
>
> *Then I just let my wife know my condition and my hospitalisation. I didn't tell her the truth until I was admitted to this department. The main reason why I concealed the truth from my wife was that I didn't want her to feel panic or anxious about my disease or to be frightened by the bad news.*
>
> *After all, I think, although I personally don't feel that my problem is a very serious one, when I tell other people about my disease, it perhaps will still sound like I am in a very severe condition, this will sound like a very terrible or scary news, right? I think that the diagnoses, such as the terms like cerebral infarction or cerebral embolism, all sound very terrible, don't they?"*

In this example, the essential purpose of the patient's temporary hiding behavior was to avoid causing or increasing his wife's potential concerns or psychological pressure due to knowing about his disease and hospital admission in order to maintain his wife's peace of mind.

However, such hiding behaviour could lead to negative consequences and make his wife unhappy about not being told about her husband's illness, potentially compromising harmony in relationships. As a result of this hiding his wife was excluded from making decisions regarding issues such as help seeking, hospital selection and initial treatment due to lack of information, thus meaning his wife played no part in early decisions.

Other behaviours were also associated with keeping peace of mind, such as searching for the best hospital.

<div align="center">Patient searching for the best hospital</div>

A 61 year old male patient, who was a manager of a drug manufacturer (or pharmaceutical company) described his experience of searching for what he perceived as the best hospital to go to.

> *Patient(10)2: "I went to the general hospital…stayed at A & E for treatment…next morning I left there and went to the specialist hospital…since there was no bed available…and a poor-organised environment in the general hospital although it's located close to my home…when I got to the specialist hospital…there was no bed again…I needed to stay at A & E for treatment and wait for a bed…I just couldn't wait any more…so I came to the current hospital…and was admitted."*

It seemed that when choosing which hospital to go to for treatment, he prioritised the quality of physical environment over the locality (or proximity/convenience) or distance between the hospital and his home. Even though it was still difficult for him to find an appropriate hospital he refused to go back to the original hospital with a physical environment that he deemed to be of poor quality.

The main reason why he searched for the hospital with a good quality ward environment was that he wanted to keep his own peace of mind, which he linked to a quick recovery. He also reported that since he worked in drug manufacturing he had experience of working with professionals in different hospitals and knowledge about different hospital characteristics such as quality of service and staff expertise, geographical location, and quality of environment. This type of knowledge aided him in making his decision. He also demonstrated a range of other behaviours.

Patient watching/comparing treatment between him or her and others

The same patient shared his use of watching and comparing the treatment given to him and that given to other patients.

> *Patient(10)8: "I once saw that other patients received the Deproteinised Calf Blood Injection by IV infusion, but I was given Vinpocetine, so I asked the doctor to explain to me why we all had cerebral infarction, but received different medication through IV therapy, and she further gave explanations about what kind of patient it was suitable to give the Deproteinised Calf Blood Injection…or the Vinpocetine for treatment." (a male patient)*

During his hospital stay, he continued to actively watch what happened to him and to other patients in relation to treatment decisions and asked the doctor for an explanation if he had any queries. Thus, he was able to ensure that he felt he had received the correct treatment, which maintained his peace of mind from the outset and throughout his stay.

When patients couldn't get the information they wanted by observing or if they did not fully trust the advice they were given then they would often check up on things.

Patient/carer checking information

A 37 year old female doctor (who had 12 years work experience) described the checking behaviour patients/carers used if they did not trust professionals.

> *Doctor(1)7: "Some patients and carers may have a little medical knowledge, and don't trust the doctor…they may search the internet to check whether what doctor said is correct…or they may go to other hospitals to consult other doctors about their examinations or treatments. If other doctors or experts agree with us, they will trust us, and find it easy to make decisions."*

According to the doctor, since some patients or carers did not trust their own doctor and the information given by him or her they would consult other authorities or get access to other information sources in order to maintain their peace of mind.

However such behaviour could also potentially alienate the professional involved and thereby compromise peace in relationships. This illustrates the relative pros and cons of differing behaviours and their original intention.

Checking behaviours could occur throughout the whole patient journey, but gradually became less frequent or disappeared with an increased level of trust towards professionals.

<center>Carer tailoring information in order to explain</center>

Explaining the meaning or purpose behind a doctor's advice on treatment to patients was one of the important responsibilities taken by carers. The following quotes described how a 52 year old daughter explained the role of nebulizer treatment to her mother in a thoughtful manner:

> *Carer6(7): "My mother was prescribed a nebulizer treatment by her doctor. The doctor said that the main purpose was to make it easier for her to cough up phlegm and reduce her coughing. But I understand that sometimes older people may feel uncomfortable wearing the nebulizer or its mask, may have a big fear of nebulizer treatment, or may feel like they are going to die due to the mask being put over their face.*

> *So I explained to my mom that she was not being given oxygen therapy via wearing the mask, the oxygen therapy would be used by doctors if patients were in a critical condition and they wanted to save patients' life. I told her that however, the purpose of her wearing the nebulizer mask was not to save her life as she didn't have an emergency or life-threatening condition, and that the purpose of her nebulizer treatment was to help her cough up phlegm easily and relieve her cough.*

> *So I think my explanation was very important and could prevent her from being frightened by the mask or the equipment and help her become more cooperative during the treatment process."*

Obviously the daughter used a tailoring process to explain the use of the nebulizer in a way that relieved any potential fears that her mother might have had about its

<center>182</center>

purpose. From the daughter's perspective this helped to maintain her mother's peace of mind and so aid her recovery.

The above examples have demonstrated how a broad range of behaviours were all motivated by the same basic desire, to maintain peace of mind. The examples below turn attention to processes aimed at keeping peace in relationships.

Key Social Processes Aiming at Keeping the Peace in Relationships

Professional hiding information from patient

Like family carers, professionals also believed that patients should be prevented from knowing bad news and frequently used hiding behaviour. This was illustrated by the following transcripts from the interview with a 45 year old female doctor who had 20 years of work experience:

> *Doctor(6)7: "We will talk to patients about certain issues, such as how to carry out stroke prevention…but we can't tell patients about poor outcome or prognosis since the patient will be severely frightened if he knows about that…for negative information, something harmful to his emotional or psychological condition, we don't tell patients about it at all. Otherwise, if the patient becomes upset or has other emotional problems after we tell the patient that negative information, the carer will complain to us, and conflicts will happen between both of us."*

According to the participant, her main purpose in hiding the negative information about a patient's poor prognosis was to avoid causing a negative emotional reaction that would inhibit recovery. However, she also pointed out the important role of hiding behaviour in keeping the peace in relationships between her and family carers. Thus, if she did reveal bad news to the patient and they subsequently became upset then the potential for disharmony and conflict between the doctor and the family was considerably increased. This illustrates that many behaviours had multiple potential motivations, further highlighting the complexity of the factors impinging on decision-making.

The example below shows how a doctor's decision to disclose information to a patient disrupted relationships with the patient's carers.

Professional disclosing information to a patient

Here the 40 year old daughter of a female patient expressed her concerns about a doctor's truth telling behaviour:

> *Carer(8)3: "Basically I always tell my mom good news, tell her happy stories, or tell jokes and funny stories to her in order to get her in a very happy mood. I also encourage her to chat with other patients staying in the bed next to hers, I suggest them to talk about happy things or to try to comfort, support or encourage each other. These, I believe, will be able to facilitate their good and quick recovery from their problems.*
>
> *However, one day, I didn't come to the hospital to see my mom because I needed to go to work on that day, a senior doctor talked to my mom about the possibility of giving percutaneous transluminal stenting to her. Then my mother was greatly frightened at hearing that and had got lots of fears.*
>
> *Afterwards, I talked to that doctor as well as other doctors, and requested them not to tell my mom about these types of things, I suggested that they never did that again. I think, on that day, if I were present during that senior doctor's ward round, I would have invited the doctor to talk to me outside the patient room immediately after she raised the topic in front of my mom. I was so sorry that I happened to not stay with my mom at that time.*
>
> *After that, my mom had told me many times that she would not like to receive surgical treatment, and she felt extremely worried about having the surgery. You know, she even felt terrible when she saw that doctors and nurses came into the room to give emergency rescue interventions to other patients. Finally and hopefully, after the neurosurgeon was invited to the consultation to see my mom's condition, they decided that my mom was not suitable for receiving the surgical treatment. I think that's okay, and hopefully she could get medication treatment anyway."*

In this example, the doctor had disclosed negative information and this had a negative effect on the patient's peace of mind As a result, the peace in relationships between the doctor and the daughter was disrupted and the daughter's own peace of mind was also reduced. Once again this shows the reciprocal relationships between various types of behaviour and people's motivation for using them.

Patient hiding preference from professionals

In order to maintain a peaceful relationship with professionals, patients sometimes used hiding behaviours to conceal their preferences. For example, a 60 year old male patient deliberately hid his preference for the IV site from nurses as illustrated in the following comments,

> *Patient(1)5: "I am too embarrassed to talk to the nurses that they should appropriately use my vein, namely they should try their best to choose the most distal vein, and then use the vein higher than the previous one…now the sites they used for my IV infusion have been located close to my wrist, but there are still several sites lower than these current ones which should have been used but now become unsuitable for IV infusion as a result."*

Given his long term experience with diseases, i.e. having cerebral infraction for 5 years and diabetes for 10 years, he might see himself as having expert knowledge on the best IV site selection for himself. However, he was reluctant to convey his preference to the nurses for fear of upsetting them and compromising their relationship. This was further reinforced by the fact that his wife worked as a radiographer in the hospital and was known to many of the nurses. In this instance the patient's decision to ignore his own preferences in order to keep the peace in relationships was unlikely to have had a major impact in terms of health outcomes but still demonstrates the importance attached to keeping the peace.

Carer searching for advice from siblings

The data suggested that participants' seeking behaviours were often closely linked to their desire to keep the peace. This is demonstrated in the following excerpt in which a 52 year old son of a male patient talked about the fact that when he was required to make a treatment decision involving risks for his father, he informed his brothers and sisters and sought their advice,

Carer(1)1: "Sometimes I need to call other brothers and sisters to ask them how to do and what to do, whether they agree with me, what their suggestions are. If they agree with me, I will give my signed consent…I can't make decisions on my own when I need to give the signed consent, such as using medications involving risks…since if some problems happen, I will not know how to explain, because people may think that 'how come you can have the final say', and will be very unhappy. The communication between family members is very important, if I don't communicate with other family members, some conflicts or problems may happen."

The main reason he asked for other family members' advice was keep the peace in relationships between himself and the wider family and to avoid being held responsible should something have gone wrong.

When decisions were perceived as difficult and involved risks the main decision-maker often needed to communicate with other family members (e.g. his or her brothers, sisters or other relatives), ask for their advice and discuss or negotiate the right course of action. The main goal was to reach a consensus and avoid potential blame or conflicts if things went wrong and keep peaceful relationships within the family. This was not necessarily problematic if the decision was not an urgent one or if the family were easily able to be contacted. However, in cases where decisions needed to be made rapidly or the family were difficult to contact then this could build delays into the decision-making process.

<div align="center">Patient/carer informing professionals</div>

Offering information regarding a patient's condition to professionals was another important responsibility for family carers. A 55 year old son of a female patient provided patient information to doctors in a clear way:

Carer(7)9: "Firstly I told the doctor the positive change or improvement in my mother's condition, and then told them the problems which still existed or were not yet solved. I clearly provided all this information to the doctor…not only told them the positive improvement of the patient's condition, but also raised my concerns and questions."

In this scenario, the son used informing behaviour to actively initiate communication with doctors, and establish a level of trust from the outset. Moreover, by providing as much information as he could the son was able to feel that he had made a valuable contribution to his mother's care, thus helping to maintain his own peace of mind. I spent a number of my observation periods with this family and my field notes contained several examples that reinforced the son's ability to provide doctors with clear and relevant information in this way. Informing behaviours such as this were of central importance.

<center>Carer advising fellow patients/carers</center>

Carers not only provided information to professionals, but also gave health related advice to other patients and carers sharing the same room or ward. For example, during my observations and field notes it was clear that a 58 year old daughter of a male patient was highly active in offering advice on healthy eating to other people. When I subsequently talked to her about why she did this she replied as follows:

> *Carer(5)4: "Here in the hospital, sometimes, I also tell other patients in the ward not to eat a high fat diet or food…you should follow the healthy diet and nutrition principles rather than your own personal preferences for food or diet. I very much would like to provide this information to everybody, and try to help them pay greater attention to these important issues."*

Creating and keeping the peace in relationships between herself and other patients/carers from different families seemed to be the major motivation behind her advising behaviour. Therefore, when she looked after her father during his hospital treatment, she actively initiated communication and deliberately engaged with others and offered them what she saw as the benefit of her long experience of looking after her father's long-standing medical needs. This also made her feel good about herself as well as creating positive relationships with the other people with whom she was in close contact for often the entire hospital stay.

<center>Fellow patients/carers exchanging information with each other</center>

Patients and family members often exchanged information with other patients and family carers sharing the same ward, something that doctors were aware of, as the

following quote shows:

> *Doctor(10)8: "Patients and carers may communicate with other patients and carers on the same ward…during their communication with each other, they will gain more understanding about the disease condition, the ward, the department, the hospital, and the health professionals working here…they will exchange information about the reputation of hospital, the quality of medical services, and the effect of treatment…this can help them make decisions.*
>
> *For example, through communicating between patients and carers, they may know that doctors in other hospitals also give patients the same treatment intervention, or that this hospital has a better environment for patients to get treatment than other hospitals, or that the staff in this hospital have a much better attitude towards patients, then they will have more trust towards this hospital and the staff, and as a result, they will be more likely or more willing to follow health professionals' or doctors' advice when making choices."*

Information exchange between patients/carers sharing the same ward was also commonly seen in the observational data and it was clear that this was an important means of initiating and sustaining relationships and important to keeping the peace in the close confines of a shared ward in which families often spent the best part of 24 hours each day.

Professional tailoring information to patients/carers in order to hide

The data suggested that doctors would tailor information to patients/carers based on their perceived trustworthiness. This might involve either exaggerating or downplaying the risks associated with a particular choice. In either cases, doctors hid the true information. A 37 year old female doctor (with 12 years work experience) described how she tailored information when making decisions with carers with different levels of trustworthiness:

> *Doctor(1)12: "Doctor's trust in patients and carers is also important…if I trust them…I will try to tell them anything or any treatment which is good for them, even though we may need to take*

the risk, patients, carers and I together may need to take the risk, I will tell carers about risks and give the patient the best treatment.

If I don't trust them…I may give conservative treatment or use the safest treatment, I don't want to cause any problems or get into trouble, therefore I give the safest treatment…I will provide them information about the safest treatment which is usually covered by the health insurance and doesn't involve any risks."

Whether doctors chose to exaggerate or downplay the risks depended on the level of trust that doctors placed in patients and carers, often based on a judgement about whether the relationship between them was likely to be affected. In these circumstances, doctors' essential purpose in tailoring information would be to keep the peace in relationships between them and patients/carers, and try to prevent possible negative consequences such as patients' poor outcomes and family complaints or conflicts.

Tailoring behaviour often strongly influenced patients'/carers' decision-making, in that they were more likely to select a doctor's preferred choice.

Summary

In exploring decision-making following stroke two core categories were identified in the present study, named 'keeping the peace' and 'making decisions'. 'Keeping the peace' emerged as the most important motivating force for all parties and was underpinned by the central Chinese cultural more of 'maintaining harmony'. This desire to keep the peace influenced the processes involved in making decisions at all stages of the stroke journey. 'Making decisions' was underpinned by three basic processes, these were: hiding, seeking and sharing. This chapter has illustrated the complex dynamics at play between these processes which often effectively excluded the older person from playing a full and active part in making decisions. Together with the important background factors explored in the previous chapter they highlight the major findings to emerge from this constructivist GT study. Before going on to consider the implications of the study attention is turned to the quality of the study and its product.

CHAPTER 7: EVALUATION OF THE QUALITY OF STUDY

In order to begin make judgements about the quality of this study two sets of criteria were used. One considers the quality of the product, i.e. the GT and the other the quality of the process. For the first the criteria suggested by Charmaz (2006) (i.e. credibility, originality, resonance, and usefulness) were used and for the second the authenticity criteria (i.e. fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity) were used as advocated by Rodwell (1998) and modified by Nolan et al. (2003b). The strategies were employed to assess the quality within this research and the extent to which I feel the two sets of criteria were met in the current study are demonstrated below.

Evaluation of GT

Given that Charmaz's version of GT method (2006) was adopted in the present study, it is logical that her evaluative criteria are applied. Charmaz (2006) sets out criteria against which the GT research outcome can be evaluated, and their main dimensions are credibility, originality, resonance, and usefulness. I will now consider my theory in relation to each of these.

Credibility

According to Charmaz (2006, p. 182-183), the following questions need to be addressed when the credibility of the study is evaluated:

- Has your research achieved intimate familiarity with the setting or topic?

Prior to the study I undertook a number of literature searches to identify the sensitizing concepts and foreshadowed questions that informed the study. I did not want these to dominate the work but rather, as Morse (1994) suggests to help me to "recognise leads without being led" (p. 27).

As I have described in the introductory chapters I already had some familiarity with the topic of decision-making and was obviously familiar with the hospital setting in which the study was conducted.

Once in the field I ensured prolonged engagement by immersing myself in the study setting and interacting with participants over a 7-month period of time. I gathered

rich, in-depth data from several data sources including interviews, observations and documents, and carried out constant comparative analysis in order to have a clear understanding of and familiarity with the research topic.

Furthermore, the breadth and depth of the findings also reflected my prolonged and in-depth engagement with participants and the study site as well as a comprehensive understanding of participants, their settings and behaviours.

- Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data.

As noted, I gathered extensive volumes of data from a range of sources over a prolonged period of time. I adopted a variety of strategies to analyse the data, all consistent with the tenets of GT. I have used extensive data to illustrate the categories developed and presented in the two findings chapters. All these strategies allowed me to gain an in-depth and extensive understanding of research participants' behaviours and experiences (Charmaz, 2006), and I feel the data were sufficient to merit the interpretations, arguments and conclusions. Ultimately of course this is for the reader to decide.

- Have you made systematic comparisons between observations and between categories?

This was achieved through the use of the constant comparative analysis method proposed by Charmaz (2006). Each piece of data was examined and compared with each other piece of related data, and the concepts or ideas emerging from the data and categories developed were compared with each other, not just within the interviews or observations of the same participant but also across the interviews with and observations of different participants.

Comparisons were also made between the observations and categories created. While the analysis process went on, patterns, links, or relationships within and between categories, and the initial hypothesis and theoretical explanations were further explored and refined through constant comparison. The use of memos and diagrams greatly aided this process.

- Do the categories cover a wide range of empirical observations?

I used theoretical sampling of individuals, topics and periods of observation to ensure that I covered a wide range of empirical occurrences. Numerous examples of these strategies have been provided in the preceding text and I believe that given the limitations inherent in any study of this nature that I have met this criterion.

- Are there strong logical links between the gathered data and your argument and analysis?

In order for the emerging theory to link closely and logically to the data, the use of constant comparison was employed. This iterative and concurrent data collection and analysis ensured that the analysis remained close to the data, that the data and the findings and interpretations fitted together, and that the resulting theory was grounded in the data.

I had regular meetings with supervisors during which we reviewed the research design and the direction or goals of the study, and emerging categories and theory, and reflected on every phase of the study. I had frequent discussions with supervisors about alternative interpretations of events in the field or various ways of interpreting the findings during the data analysis in order to develop a theory grounded in the data. I shared my ideas with them, and they helped to guide me about what to do more next. Reflections and interpretations of the data and findings, insights and emerging categories were all recorded in the form of memos or meeting notes as the study progressed.

To ensure strong logical links between the data, analysis and interpretations, member checking was another important strategy undertaken in the current study. The way I carried out this strategy with the participants is addressed separately below, under the heading 'member checking'.

- Has your research provided enough evidence for your claims to allow the reader to form an independent assessment – and agree with your claims?

In order to give enough evidence for the readers to judge and form an independent conclusion about the credibility of the interpretations, the research findings have been presented in detail in terms of core categories, key social processes and major factors with supporting verbatim quotations from participants. Interactions,

relationships and dynamics between core categories and key processes are illustrated with diagrams. Much of the information about the procedures by which the study was conducted and data collection and analysis processes has been described in the methodology chapter in an attempt to add further transparency to the research process (Patton, 2002).

Member checking

Credibility is also concerned with the extent to which the links between the data and the conclusions are strong and logical and the extent to which the researcher accurately interprets the collected data as viewed by participants (Charmaz, 2006). In the present study, I strove to achieve this and ensure that a good quality GT was produced through ongoing member checking during which participants were asked questions related to data, emerging categories, interpretations, final findings, conclusions and theory (Lincoln and Guba, 1985). At all times I encouraged an active negotiation between myself as researcher and the participants so that the developed theory would be based on our collective efforts.

Member checks were conducted throughout all phases of the study, for example,

- During interviews by rephrasing what participants had said and reflecting and checking my interpretations back to them, and asking whether they really meant that or whether that was what they were saying,

- By introducing issues which were raised by participants during earlier interviews and considered important into subsequent interviews, and allowing current participants to make comparisons with their own experience,

- Towards the end of the interview by briefly summarising the key points which had been discussed, and checking out my understanding with participants,

- During periods of observation by inviting participants to comment on my interpretation of events and checking for meanings.

Therefore, member checking was a continuous and on-going process in which I took data and their interpretation back to the participants to ensure their accuracy and enhance the credibility of the study (Rodwell, 1998; Kvale, 1996).

The overall research findings were also shared with participants for their comments and feedback. For example, after I finished the initial analysis of the data collected during the 1st phase field work, due to the long distance between myself, who was in the UK and my participants who were in China, I sent a summary of major findings from their particular individual interview and the study as a whole to professionals via email and encouraged them to read through the summary and identify any of the constructions with which they disagreed, and sought their feedback. Staff members were also invited to add any additional information or correct any misunderstandings or misinterpretations. Fifteen out of 20 staff gave me feedback, which was then recorded for further analysis.

As a relatively novel attempt, the email communication served the purposes of not only verifying accounts and checking main ideas or categories, but also undertaking co-construction of the findings with participants. The professionals involved in this process were not just asked if they agreed or disagreed with the findings, but also to elaborate upon any points that they thought were not sufficiently developed.

During the 2nd phase field work, I followed a similar pattern and at this stage, member checking was also conducted with the new participants (i.e. professionals, patients, and carers) recruited through theoretical sampling. Here I took a slightly different strategy to work with participants. At the end of interview I presented the major ideas found during previous data analysis which had not been mentioned by the current participants, and asked for their perspectives and thoughts.

I also sought to contact prior interviewees via the telephone or arranged to meet them at OPD appointments in order to further seek their views. In this way the majority of staff (20 out of 25 staff) and about half of patients and carers (15 out of 28 carers and 9 out of 19 patients) were involved in the member checking process.

Finally, towards the end of data analysis, I presented to the professionals the overall key findings from both two data collection phases and invited their comments via email communication (Appendix 27). Firstly, I explained what I would like them to do and then presented them with a list of questions to think about when reading the findings. Then I briefly described the main findings in terms of the key idea of maintaining harmony, the major processes that people used when making decisions, information and knowledge gained and used during decision-making process, people involved in decision-making, types of decisions that were made, and important factors influencing decision-making processes.

This was an important element of the co-construction, but the use of email for this purpose represents a fairly innovative and novel application of technology that possibly merits further exploration as it seems to offer considerable promise. Eleven (nine doctors, one nurse and one physiotherapist) out of 19 professionals to whom the summary of findings were sent replied to the invitation and gave their feedback. The processes and factors described made sense to them and they could recognise them from their own daily work. They further believed that the processes and factors captured the main influences on decision-making and could be used to help patients, carers and professionals make decisions more effectively and feed into the future training of professionals. The participants also occasionally suggested some new information. A summary of the professionals' feedback is included in Appendix 28.

Originality

Charmaz suggests that researchers should ask the follow questions when they evaluate the originality of their study (2006, p. 182-183):

- Are your categories fresh? Do they offer new insights?

In terms of the originality, this study is among the first to be undertaken in a Chinese context to explore decision-making from the perspectives of older patients with stroke, family carers and health professionals. Many of the categories, concepts and processes presented in the study are driven by the Chinese cultural tradition of maintaining harmony, and the analysis offers fresh insights into the full impact that this long-standing belief continues to exert in modern day China.

- Does your analysis provide a new conceptual rendering of the data?

Yes. The findings to the best of my knowledge have not yet been identified and described previously, and so the analysis therefore provides a new conceptual rendering of the rich data. As will be discussed later some of the categories, for example 'seeking' have been previously described in the context of stroke (Brereton and Nolan, 2002; 2003) but the current study both offers a wider interpretation of the process and develops it in a differing cultural context.

- What is the social and theoretical significance of this work?

This will be discussed in the next chapter.

- How does your GT challenge, extend, or refine current ideas, concepts, and practices?

This will also be considered in the next chapter.

Resonance

The specific criterion of the resonance of a GT study includes attention to the following points (Charmaz, 2006, p. 182-183):

- Do the categories portray the fullness of the studied experience?

Resonance was achieved by ensuring data saturation through theoretical sampling (Glaser and Strauss, 1967) and by verifying the completeness of the findings and the emerging theory through member checking with the participants. The participants' feedback suggested that the findings comprehensively captured the main influences on decision-making and fully portrayed their decision-making experiences.

Resonance was further strengthened through providing sufficient data (Geertz, 1973) and presenting sufficient background information about the participants and the research context and setting (Krefting, 1991) in the research report.

- Have you revealed both liminal and unstable taken-for-granted meanings?

Participants' feedback from member checking suggested that the study findings helped discover a number of hardly perceptible and taken-for-granted meanings of their experiences, particularly amongst those professionals involved and this helped them to think through and reflect about a number of practices to which they rarely gave a second thought.

- Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?

Yes. Resonance was also sought by revealing the contextual links between larger collectivities or institutions and individual lives. For example, the findings indicated that, as one of the major influences on the decision-making process of an individual, culture was a complex and multilayered concept that operated at several levels such as national level (e.g. the idea of harmony), regional level (e.g. the geographical custom), professional level within an acute care hospital (e.g. communication style of a team), family level (e.g. family pattern of working), and personal level (individual values of beliefs). All these impacts were found to be closely linked to people's individual decisions.

- Does your GT make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds?

This was achieved by verifying accuracy of the findings and the emerging theory through member checking with the participants. The participants' feedback suggested that the processes and factors described made sense to them and that they could recognize in their daily work.

<div align="center">Usefulness</div>

Usefulness speaks to the practicality of the theory, and examines the following issues (Charmaz, 2006, p. 182-183):

- Does your analysis offer interpretations that people can use in their everyday worlds?

The results of the study and the emerging theory were confirmed for usefulness with the participants during member checking. Following completion of data analysis, the study findings were presented to the participants, and minor alterations were made according to their feedback.

Participants commented that they could see themselves and their stories within the substantive theory, and thought that the findings portrayed what they experienced when they made decisions, and that they were able to recognise the specific processes or factors from their own day to day decision-making practices. Participants further believed that the findings offered useful information and could be used to help patients, carers and staff make decisions more effectively, in the

training of professionals, and in producing information, advice or guidance for patients and carers.

- Do your analytic categories suggest any generic processes?

The generic processes of hiding, seeking, and sharing were identified and their dimensions have been fully explored.

- If so, have you examined these generic processes for tacit implications?

This will be considered in the next chapter.

- Can the analysis spark further research in other substantive areas?

This will also be explored in the next chapter.

- How does your work contribute to knowledge? How does it contribute to making a better world?

This is another consideration for the next chapter.

Based on the above I believe that my study can be said to have met the criteria described by Charmaz (2006). I will now move on to consider the question of authenticity.

Evaluation of Authenticity

This section considers the quality of the research process itself by exploring the extent to which the study meets the authenticity criteria proposed by Guba and Lincoln (1989) for evaluating research within the constructivist paradigm, including: fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity (Table 7.1).

**Table 7.1 Authenticity Criteria for Evaluating Research
within the Constructivist Paradigm**

Fairness – the extent to which different constructions and their underlying value structures are solicited, obtained and inform the results.
Ontological authenticity – the extent to which individual respondents' own emic constructions are improved, matured, expanded and elaborated.
Educative authenticity – the extent to which individual respondents' understanding of and appreciation for the constructions of others outside their stakeholder group are enhanced.
Catalytic authenticity – the extent to which action is stimulated and facilitated by the (research) process.
Tactical authenticity – the degree to which stakeholders and participants are empowered to act.

Based upon Guba and Lincoln (1989).

These criteria were suggested by Guba and Lincoln as being the most appropriate for a constructivist study. However, Nolan et al. (2003b) argued that if a foundational assumption of constructivist inquiry is that all the stakeholders should be part of the process of producing the knowledge (Lincoln, 2001), then a key issue is that the language used to describe key processes should be accessible to all participants. They suggested that the above criteria would fail on this count and suggested a rephrasing that is captured in the table below.

Table 7.2 A comparison of the Terms Used by Guba and Lincoln (1989) and Nolan et al. (2003b) in Relation to the Authenticity Criteria

Term used by Guba and Lincoln (1989)	Terms used by Nolan et al. (2003b)	Definition of term
Fairness	Equal access	All viewpoints are represented even-handedly
Ontological authenticity	Enhanced awareness of the position of self	Participants understand their situation in more informed ways as a result of participation in the research
Educative authenticity	Enhanced awareness of the position of others	Participants understand the situations of others in more informed ways as a result of participation in the research
Catalytic authenticity	Encouraging action by providing a rationale or impetus for change	Participants have a greater insight into actions that they might take to change their situation as a result of participation in the research
Tactical authenticity	Enabling action by providing the means to achieve change	Participants feel empowered and enabled to act as a result of participation in the research

Source: Brown Wilson and Clissett (2011, p. 679).

These principles are closely aligned with the constructivist epistemology which undergirds the current research method, and are concerned with participants having benefitted by participating in the study. They serve to reflect the effectiveness of the research, and have been used to assess the quality of research that promotes user participation (Hanson et al., 2006), in particular older people's involvement in care home research (Brown Wilson and Clissett, 2011).

However Nolan et al. (2003b) went beyond a rewording of the criteria and also argued that they should be applied at all stages of the research process and not just the conduct of the study. This is captured in the matrix below.

Table 7.3 The AVS Model Matrix

	Planning	Process	Product
Equal access			
Enhanced awareness of self			
Enhanced awareness of others			
Encouraging action			
Enabling action			

(Hanson et al., 2006; Nolan et al., 2003b)

This approach was used in this study.

Equal access

Equal access emphasises the fair treatment of the participants, namely that all viewpoints are represented even-handedly (Nolan et al., 2003b). Within the current study, efforts were made to ensure that the voices of all stakeholders with an interest in older stroke patients' and carers' experiences of making decisions were heard, in other words, all their opinions sought, listened to, valued and included.

In the planning of the research

The constructivist approach is concerned with the unique understanding and experience that each individual participant brings to the field. At the beginning of the study when selecting participants through purposive sampling, I made attempts to engage as wide a variety of participants as possible.

The people involved were older patients with stroke, their main family carers, other family members who were present during the interview, and a wide range of different staff members such as the physicians of various grades, nurses (e.g. head nurse, office nurse who was usually considered as the deputy head nurse, and general nursing staff), physiotherapists and acupuncturist.

However, due to limited resources and time scale I did not include people with aphasia, with cognitive impairments, or other serious conditions, so these types of patients were denied access to this study.

During the research process

The semi-structured interview technique that I used, along with the theoretical sampling when new ideas developed, emerged and were added, enhanced the equal access both to diverse ideas and different people. The inquiry was organised to elicit participants' unique explanations of their experiences in their own decision-making practices and I employed techniques previously described to ensure that they were given every opportunity to take part in co-construction on the theory. As was evidenced in the findings chapter, most of these stake-holders had had their voices, views and concerns represented in the findings as required by the criterion of equal access.

Equally important were the use of multiple data resources (such as interviews, observation, informal communication, and email contact with some of the professionals) and rich descriptions which allowed me to account for participants' diverse perspectives as comprehensively as possible.

In the product of the research

In the current study, although efforts were made to ensure that participants were involved across all stages of the research (i.e. the data collection, analysis and writing-up phases), not all three groups of participants had an equal access to the results of the study, especially the final summary of the overall key findings.

Although the majority of the professionals and nearly half of the patients and carers were involved in the first member checking process, for the second only around half of the professionals were contacted by email and gave their input. Consequently, the final version of the key findings was only checked with staff and this represents one of the limitations of the current study. Therefore, this study was considered to only partly meet the requirement for equal access.

In the future more effective strategies need to be developed in order to enhance access to the final product or the wider report of a study when it is ready. These important issues will be addressed in the discussion and conclusion chapter.

This requires that participants understand their situation in more informed ways as a result of participation in the study, reflecting the degree to which participants' own constructions or understandings are developed, enhanced or expanded (Nolan et al., 2003b).

In the planning of the research

In planning the research I sought to adopt an interview style and approach that would enable participants to generate accounts likely to ensure that new insights emerged. At this stage I did not know if this would be successful.

During the research process

In the current study enhanced awareness of self was assured through the use of ongoing member checking procedures. For instance as already discussed, during interviews I rephrased what participants had said and checked my interpretations back to them, and asked whether they really meant that; then towards the end of the interview, I briefly summarised the key points which had been discussed, and checked out my understanding with participants through asking follow up questions.

Introducing examples identified during my observation of a participant into the interview with the same participant was also used to maximise opportunities for new insights to emerge. Feedback from participants suggested that these strategies had proved successful and that by engaging in the study they had a fuller understanding of their part in the decision-making process.

In the product of the research

Enhanced awareness of self at this stage is about engaging participants in a discussion of the findings. This was achieved through encouraging them to think about the position or views of themselves or their own group during the final member checking toward the end of the study. By reflecting on the findings, a majority of the professionals believed that they were better able to gain an in-depth understanding about their experience of decision-making and the various factors which had shaped and created those experiences through participating in the study and discussing their stories.

Enhanced awareness of others

This refers to the fact that participants should understand and appreciate the situations of others in more informed ways as a result of participation in the research (Nolan et al., 2003b).

In the planning of the research

I was aware that developing interview schedules as the data analysis progressed by introducing divergent views from other people might enhance the awareness of others.

During the research process

In this study, the ongoing member checking also promoted enhanced awareness of others, as it was in this process that participants got to hear the constructions of realities or decision-making role of others, and had an opportunity to learn about other's stories. During interviews, sometimes I introduced the examples identified during my field work, and then allowed the current participants to make comparisons with their own experiences and share their perspectives with me. For example, through my observations as well as interviews, I understood how patients or carers made decisions about diet in different ways, sometimes either the patient or the carer took the lead, whilst at other times both of them had a discussion. Alternatively, they might need to decide whether to prepare the food at home for the patient or buy the food from a restaurant for the patient. Therefore, when I introduced a couple of such examples during interviews, this would allow the participants to make a comparison between how they made decisions and how their counterparts considered similar issues.

In the product of the research

This was again addressed through the strategies to engage participants in co-construction as previously described. For example, during member checking, a physician's response revealed his greater understanding and new appreciation of the experience and perspectives of patients and carers. He suggested that participating in the study gave him an opportunity to gain new understandings.

Certainly many participants expressed appreciation for the opportunity to talk with me and felt that they had benefited. It seemed that the professional participants who talked about seeing things differently had gained an appreciation of the way in which other colleagues, patients or carers saw the world, reflecting the increased awareness and understanding of others' situation and values.

Encouraging and enabling action

A vital aspect of constructivist research in general, and GT in particular, is that it should have the potential to encourage action, that is things should potentially change as a consequence. This criterion seeks to assess the extent to which action is motivated and stimulated, and examines whether participants have a greater insight into actions that they might take to change their situation as a result of participation in the research (Nolan et al., 2003b). The related criterion is that participation or the results of a study should enable action. This criterion is considered to be satisfied when participants feel empowered and enabled to act as a result of participation in the study (Nolan et al., 2003b). As this study was not action oriented per se no specific processes were built into to it to meet these two criteria. However, participation and the results should have the potential to meet these criteria and there were indications that this was clearly the case.

For example, a patient gave constructive suggestions on improvements to medical practice by pointing out that in order to better help patients and carers make health related decisions, doctors should give them clear and detailed explanations about treatments, should have patience with them, and should pay greater attention to their communication style when delivering the information. A carer also pointed out the weaknesses that existed within the current hospital context, such as the inconvenience of preparing food for their older relatives, and the difficulties of bearing the burden of caring for their older relatives encountered by busy working adult children, and suggested that the hospital staff needed to make great efforts to address these problems and better improve the quality of their services. Similarly, according to a physician, the findings stimulated her to realise their attitudes towards patients and carers as well as their communication skill or techniques when they made decisions with patients and carers could be improved. She identified a range of potentially positive outcomes resulting from these changes, such as more harmonious relationships between professionals, patients and carers, strengthening patients' and carers' trust in professionals, and helping patients and carers make better and faster decisions.

There was also some evidence that actual behaviours had changed. For instance, compared with her decision-making patterns that were observed during the first stage of data collection, one physician was found to have made changes based on my observational field work during the second phase data collection. For example, previously during her ward round, she spent less time communicating with patients and carers but more time talking with colleagues, in particular teaching or giving instruction to junior staff or medical students, and so it was difficult for patients and carers to get enough information to make decisions. However, in the second round of observations I noticed that she spent more time actively interacting with patients and carers, demonstrating more patience and enhanced communication skills.

Finally, specific strategies used to engage participants in a discussion of the final product as well as the potential for this product to achieve the authenticity criteria will be discussed in more detail in the concluding chapter.

Summary

In spite of the fact that some of the criteria were not fully achieved, this reflection suggests that the findings and interpretations accurately and comprehensively captured stakeholders' experiences within the context of stroke care, offered new insights into current knowledge, could be used to create positive changes to and improve the decisions that were made in their daily practice via prompting reflection, discussion and action on the part of research participants. The majority of the participants recognised the role of participation in the current study in helping them to gain new understanding and to think about their decision-making in differing ways. The feedback from a wide range of lay and professional audiences also indicate that the findings had currency, resonance and value within the current context of decision-making practice, and that they provided new forms of insight and understanding. Having reflected on the quality of the study, I will now discuss my findings in relation to other pre-existing and concurrent literature in the field and address how the findings of the present study can contribute to the development of theory and practice.

CHAPTER 8: DISCUSSION AND CONCLUSION

Introduction

The main findings and the resultant theory that emerged as a result of the numerous interviews and periods of observation have been described in Chapters 5 and 6. These have provided insights into the major contextual and background factors shaping decision-making within the 2-3 week period of hospitalization following an acute stroke (i.e. people involved, types of decisions, knowledge used, the influencing factors in particular the Chinese cultural tradition of maintaining harmony), the core categories (i.e. making decision and keeping the peace) and how they interact to influence the decision-making process.

Within this chapter, I will consider the above in the light of the existing literature. This is followed by an exploration of a number of important ideas within the health care literature, including: awareness contexts; the role of partnerships in the western health care context; and relational practices and their relevance to the experience of older people with stroke, their family carers and professionals in relation to the decision-making processes.

The implications of the current study for practice, education, policy, as well as areas for future research will be highlighted. In the last section, the major conclusions drawn from the study will be outlined and considered.

Before doing this a brief resume of the theory developed in this thesis is presented.

Summary of the Theory

The overall purpose of this constructive GT study was to explore the processes via which older people with stroke, their family carers and health professionals make decisions in an acute care context in China. Based on the numerous interviews and periods of observation described in Chapter 4, two core categories, i.e. making decisions and keeping the peace and their sub-categories were identified, and the close interactions between both of these categories and the role of Chinese culture in shaping those processes and dynamics was highlighted. The above findings formed the key components of the emerged GT.

The current study suggests that in order to effectively make various decisions during the 2-3 week hospital stay, older patients with stroke, their family carers and professionals engaged in a number of key social processes in an attempt to make decisions whilst also 'keeping the peace'. The three main processes were hiding, seeking and sharing and their specific sub-categories (e.g. permanent hiding, temporary hiding, and tailoring to hide for hiding process; searching, watching/comparing, and checking for seeking behaviour; and informing, advising, exchanging, and tailoring to explain for sharing process).

The study indicated that the most important goal, albeit sometimes implicit, for all three groups of people during the patients' journey was to 'keep the peace', in order to be congruent with the central Chinese philosophy of maintaining harmony in all aspects of life. Keeping the peace related both to 'peace of mind' and 'peace within relationships'.

In addition to the above key findings, a range of important contextual and background factors were influential in the overall decision-making processes, including: the people who were involved; the types of decisions that were made; the types of knowledge that informed such decisions; environmental factors; medical/treatment related factors; patient-, carer- and professional-related factors; and culture and trust which operated at different levels and had impacts on decision-making in different ways.

The results highlighted the complex and interdependent nature of many of the above processes but consistent with the goals of constructivist GT, I have sought to unravel these complex processes and to present them in a way the 'speaks to' participants using ideas and concepts that they understand (Charmaz, 2006). Feedback from participants suggests that this has been largely achieved and I feel that the study has addressed the initial foreshadowed questions identified in Chapter 3. I will now consider the theory in the light of the existing literature, especially that relating to decision-making.

Processes of decision-making and keeping the peace

Keeping the peace

The findings clearly indicate that the single most important motivating factor in making decisions was to keep the peace by maintaining harmony. This offers some

new insights into the central role of harmony within Chinese health care, but there are also some parallels with earlier work.

For example, Bowman and Singer (2001) found that in order to maintain a harmonious inter-familial relationship, older Chinese patients were unwilling to designate a surrogate decision-maker due to the concern that conflicts within family might develop if there was disagreement between the surrogate decision-maker and other family members as they believed that consensus among children was important for ensuring good decision-making.

In addition to the idea of maintaining harmony within family groups, a harmonious relationship between the patient and friends was also highly valued in Japan. Takahashi et al. (2003) found that one of the major factors related to patients' decision to accepting an influenza vaccination included recommendation by family and/or a close friend, and having family and/or friends who had previous vaccination experiences. This was partially attributed to the fact that people from Japan or other Asian backgrounds considered maintaining a harmonious relationship with family or friends as the most important consideration.

Patients' desire to maintain a harmonious relationship with doctors was demonstrated in the study by Ngo-Metzger et al. (2004), who reported that lower levels of participation in health care decision-making amongst Americans of Chinese, Filipino, Asian Indian, Japanese, Vietnamese, and Korean descent compared to their white counterparts was primarily due to the desire of the above groups to maintain good relationships and avoid potential conflict with doctors. They argued, as had been suggested by others, that to maintain a harmonious relationship with doctors, Asian patients showed their respect by nodding and smiling at doctors (Kagawa-Singer, 1996), but were reluctant to openly express their disagreement with the doctors' treatment plan (Mull et al., 2001). As a result, doctors often misunderstood or underestimated their patients' preferences for participation.

According to the study by Ruhnke et al. (2000) and a more recent one by Weng et al. (2011), the idea of maintaining a harmonious relationship with patients and family members and maintaining harmony in a patient's mind had a great impact on doctors' decision-making behaviours. For example, Ruhnke et al. (2000) reported that Japanese doctors preferred to disclose cancer diagnosis to family members rather than patients; and in the study by Weng et al. (2011), the majority of Chinese

doctors working in an ICU indicated that they would tailor medical information based on individual patient's specific prognosis rather than provide complete medical information to their patients.

The findings in both studies consistently emphasised the need to avoid open discussion about bad news and transmitting unnecessarily damaging or sensitive information about diagnosis or prognosis to patients with cancer or other serious conditions. It was argued that the main purpose behind these behaviours was both to maintain harmony in the patients' mind, but also maintain a harmonious relationship between doctors and family members during a stressful period of the patient's life. These authors stress the powerful influence of traditional cultural values of creating and maintaining harmony among Asian countries (Weng et al., 2011; Ruhnke et al., 2000).

The extent to which the above studies mirror those found in my work is striking and reinforces the ongoing role of widely held cultural beliefs and their impact on numerous dimensions of life, including health care.

Harmony has been a highly prominent theme in traditional Confucianism for thousands of years (Chen and Starosta, 1997), and strongly influences cultural beliefs within other Asian countries (such as Japan, Korea) as well. It is clear that the idea of maintaining harmony, especially a harmonious interpersonal relationship and harmony within the self, in Chinese culture significantly influences health care decision-making behaviours among patients, family carers and professionals of Asian background. This has been noted in other studies but the current work appears to offer a number of new insights that allow a greater breadth and depth of understanding, especially about behaviours such as hiding. It will be suggested later that these can be seen as forms of 'relational practice' that need to be explicitly recognized and addressed by health care professionals.

Consideration is now given to the core category of decision-making.

Making decisions

The key processes involved in making decisions, those of hiding, seeking and sharing have already been considered in depth and related processes were identified in 4 studies that emerged from the literature that was consulted as data collection progressed (Popejoy, 2011; Weng et al., 2011; Chang and Schneider, 2010; Hubbard

et al., 2010). These and related studies are considered with reference to the major processes identified in the current work.

- Hiding

No literature that explicitly used the concept of hiding as it related to patient/carers behaviours were found, although later this notion will be discussed in relation to Glaser and Strauss's original idea of 'awareness contexts' (Glaser and Strauss, 1967). However, in addition to patients and carers the current study suggested that hiding was commonly used by health professionals and involved either downplaying or keeping bad news from patients. Japanese studies have reported a similar hiding process, in which doctors did not tell cancer patients their true diagnosis information, but told the families first and then let families decide whether to tell patients the truth (Elwyn et al., 2002; Ruhnke et al., 2000).

The main purpose behind the Japanese and Chinese professionals' hiding behaviours was to maintain patients' happy mood or harmony which was closely linked to a good recovery, whilst also maintaining a harmonious relationship with families. However, as a result, patients could not make an informed decision due to lack of required information. Other studies suggest practices similar to that described as 'tailoring to hide' in my work. A recent and interesting example was the study on decision-making among Chinese doctors working in an ICU (Weng et al., 2011). The findings suggested that only 19% of doctors gave complete medical information (e.g. diagnosis, treatment, prognosis) to patients, with most providing individually adjusted or specifically tailored information based on the patient's disease, clinical condition, and prognosis. The researchers argued that the doctors' underlying purpose seemed to be to hide negative information from patients and so avoid them from hearing bad news. This seems a similar process to 'tailoring to hide' identified in the current study. Both studies once again demonstrate the significant role of Chinese cultural tradition of maintaining harmony in shaping professionals' decision-making practices.

Interestingly in another recent study, a similar process of tailoring to hide was also identified, but was found to be used by older patients and their spouses rather than professionals. In Popejoy's (2011) study examining decision-making on discharge planning among hospitalised older patients, families, and health professionals, 'deciding what to tell' was an important theme identified and meant that since older patients and their spouses were reluctant to burden their children but wanted to

independently manage potential problems after discharge home, they were unwilling to provide detailed information about their care needs to their children and tried to prevent their children's involvement through limiting what they told them.

In her study, although she used a different phrase of 'deciding what to tell', Popejoy (2011) described an important idea which was similar to the process of 'tailoring to hide'. The findings of both her study and the current one illustrate a similar process, which involved deliberately altering or adapting information to meet a specific need or to suit a particular purpose, namely, to prevent full disclosure of information. However, Popejoy's study was undertaken (2011) in the US, and the majority of participants were white native Americans therefore it seems that the idea of avoiding burdening others, especially young people, is common in both China and the US.

- Seeking

The idea of seeking in stroke care was first presented by Brereton and Nolan (2002; 2003) and described how carers of stroke survivors were found to actively seek information, help, support, and partnership from both families and professionals in order to make better care decisions for their spouses. This work in part informed the current study and my findings not only reinforced the idea of seeking, but also extended its dimensions by adding the categories of searching, watching/comparing and checking processes, and noting that seeking could be undertaken not only by carers but also by patients and professionals.

  o Searching

Other studies have also highlighted how stroke patients' and carers' employ behaviours similar to seeking or searching. For example, patients were found to actively seek medical help at the time of stroke (Moloczij et al., 2008; Olofsson et al., 2005), while carers would search for advice or support from professionals when making treatment decisions (Rogers and Addington-Hall, 2005).

Echoing the searching behaviours used by stroke patients and carers in the current study, the above findings in the existing literature were largely related to searching for medical help at the onset of stroke or proactively searching for health-related information from different sources. However, due to the nature of the Chinese

health care system participants in my study also sought a particular hospital. Studies exploring a wider range of health related decisions have also described a range of seeking type behaviours, as indicated below:

Patients'/carers' searching for professional help such as nursing home placement (Chang and Schneider, 2010) or informal help such as hiring a helper at home (Kao and Stuifbergen, 1999).

Patients'/carers' searching for health-related information from a range of sources:

> Professionals, medical journals, newspapers, the Internet (Chang and Schneider, 2010; Hubbard et al., 2010; Zhang et al., 2010; Sahlsten et al., 2009; Smith et al., 2009; Chang et al., 2008; Larsson et al., 2007; O'Connor et al., 2003; Ross et al., 2001);

> Family, loved ones, friends or trusted colleagues (Chang and Schneider, 2010; Lown et al., 2009; Sahlsten et al., 2009; Chang et al., 2008; Larsson et al., 2007; O'Connor et al., 2003; Ross et al., 2001).

Professionals' searching for information about patients' health condition, preferences, needs, opinions and experiences from patients themselves (Zhang et al., 2010; Lown et al., 2009; Sahlsten et al., 2009; Larsson et al., 2007; Elwyn et al., 1999).

With regards to the two types of searching processes concerning, patients'/carers' searching for a suitable hospital and professionals' searching for patients' or carers' knowledge or expertise, these processes were only demonstrated in the current study, and have not been reported by other researchers.

> o Watching/comparing

In the current study, another type of seeking process, mainly used by patients and carers, was watching/comparing. As the data indicated this was often used by patients to compare the treatment they were receiving with that received by other patients. Whilst similar behaviours do not seem to have been reported elsewhere, Brereton and Nolan (2002) described how carers would watch and compare the care other stroke survivors received and compare it with that of their relative. Other studies have described how carers in particular watch and compare care in other

care settings such as nursing homes (Sandberg et al., 2001).

Chang and Schneider (2010) found that when there were several alternative care services available for people with dementia (e.g. nursing home, dementia day care centers, respite care, home care, home assistance programs, and hiring a foreign worker for the home), family carers would examine and compare the pros and cons of them in terms of quality of care, level of assistance, caregivers' health status, financial burden, and affordability of the different options before making their choice (Chang and Schneider, 2010).

Watching and comparing may be more common in China because family members often spend 24 hours a day on the unit and have considerably more opportunities to engage in such activities. This is especially true in the context of stroke where families are generally the main sources of basic daily care and support throughout the whole stroke trajectory from admission until discharge home (Pang et al., 2000).

  o Checking

Patients and carers were found to use checking processes in different ways, such as verifying or confirming the accuracy of information given by professionals (e.g. doctors) by consulting another source or authority; checking the accuracy of medication thoroughly before taking it or giving it to patients; or checking with other fellow patients about their experience of going through particular procedures in order to gain information helpful for making their own decisions.

Checking behaviours were not found in the literature on stroke, but two studies from the literature on other areas of health care decision-making reported similar findings. For example, Rydeman and Tornkvist (2009) found that when older people and their carers distrusted information given and decisions made by professionals, they would actively check information through consulting with other physicians, nurses or pharmacists, or reading books or other written materials.

Similarly, Smith et al. (2009) suggested that, by holding the belief that professionals were fallible and not "gods" (p. 1808), some patients with higher education levels did not readily accept suggestions or blindly follow instructions, and would verify and confirm the credibility of information provided by professionals through independently seeking knowledge via the Internet or another medical professional. The authors also suggested that this type of behaviour is likely to increase

significantly as access to alternative sources of information expands.

- Sharing

  o Informing

Similar findings relating to professionals' informing processes were identified in both the literature on stroke care and the current study. Although other researchers did not use the term informing, their findings suggested similar processes. For example, providing information to stroke patients was identified as an important strategy used by professionals to facilitate patient participation in decision-making (Almborg et al., 2008; Health Care Commission, 2006; Proot et al., 2000a; 2002).

However, information in the current study was primarily given to carers and not patients, especially if it related to bad news. This related not only to the desire to maintain harmony but also accords with the family-oriented cultural tradition in China where family members are more likely to take the lead in health care decision-making (Chen and Fan, 2010). Therefore, consistent with the above findings, the wider literature suggests that one of the most effective strategies used by professionals to facilitate older patients' or carers' participation in decision-making is to provide adequate information (Tutton, 2005; Davies and Nolan, 2003; Walker and Dewar, 2001). However, the findings of the current study resonate with the characteristics of the Chinese style of informed consent described by Cong (2004), who found that a majority of Chinese doctors preferred to inform family first, and then whether, what, and how the patient should be informed depended on the families' decisions.

Other forms of informing behaviour were identified in the current study and to some extent are also described in the wider literature. For example, Hasselkus (1992) reported that carers of older patients actively contributed to decision-making by providing patient-related information to doctors.

  o Advising

As in this study, the literature on stroke care noted that advising processes were widely used by patients (Hedberg et al., 2008), carers (Hedberg et al., 2008) but in rather different ways. In the study by Hedberg et al. (2008), patients and carers were found to participate in decision-making mainly through giving advice to

professionals during discharge planning meetings. However, in the current study, the advising process mainly occurred between patients and carers within the same family or those sharing the same room or the same ward.

In the wider literature, other researchers have reported that one of the strategies used by professionals to facilitate older patients' or carers' participation in decision-making was by giving them advice to allow them to make decisions (Rotar-Pavlič et al., 2008; Davies and Nolan, 2003). This advising behaviour was also widely used by a majority of health professionals in the current study, but mainly to carers.

Two studies in the wider literature reported on advising processes mainly used by carers (Takahashi et al., 2003; Hasselkus, 1992). For example, Hasselkus (1992) demonstrated that carers of older patients actively participated in decision- making through recommending diagnostic tests or suggesting treatment to doctors during the consultation. This finding was similar to that in the study by Hedberg et al. (2008), where stroke patients and carers gave advice to professionals during the discharge planning meeting.

- o Exchanging

This study suggested that exchanging information was mainly used by patients and carers, either within the same family or those with whom they shared a ward. This was commonplace and one of the primary ways in which patients/carers initiated and sustained harmonious relationships with others in a similar situation. This has not been widely reported elsewhere and again may be a result of the Chinese health care system and the fact that families often care for and stay with patients throughout the whole hospital stay (Lee, 2001; Pang et al., 2000).

As described in Chapter 6, information exchange could play both facilitating and inhibiting roles in patients' and carers' building trust with professionals. As this was widely used by patients and carers, professionals need far greater awareness of this major source of information.

- o Tailoring to explain

Tailoring to explain has also been described in prior work but does not seem to have been used as extensively. As already noted in a recent study on decision-making by Chinese doctors working in an ICU (Weng et al., 2011), most doctors were found to

provide individually adjusted or specifically tailored medical information (e.g. diagnosis, treatment, prognosis) to patients based on their educational level and expectations. Similarly Lown et al. (2009) reported that, in order to facilitate patients' active involvement in making decisions, professionals would adjust information to patient's needs and preferences by using language that was understandable to the patient, and adjusting the type and volume of information shared, in order to ensure clarity and common understanding. Similarly, patients in Larsson et al.'s (2007) study also agreed that giving information was an important strategy facilitating their participation in decision-making about nursing care.

Earlier work by Elwyn et al. (1999) described how doctors would use different strategies to judge a patient's preferred choice before tailoring the type of information and the preferred format (e.g. verbal, numerical, and graphical information).

The findings in the above four studies describe a similar process of 'tailoring to explain', which enables professionals to provide patients with easy-to-understand information to meet their individual needs.

In terms of carers' use of the process of tailoring to explain, only one study reported relevant findings. Hubbard et al. (2010) found that during consultations with professionals, when some cancer patients found it difficult to understand information given by professionals, carers would assume a dominant role in digesting medical information and then explain and relay that information to patients to help them to make treatment decisions. In the current study, carers used this type of tailoring to achieve different purposes but these primarily related to their desire to maintain harmony.

- Summary

A comparison of the main processes identified in this study with those previously described in the literature has identified both similarities and differences. This study has expanded upon previous work and in particular related it to a Chinese cultural context in which the Confucian ideal of maintaining harmony exerts a considerable influence.

Harmony has been a prominent theme in traditional Confucianism for thousands of years (Chen and Starosta, 1997) and the above findings all indicated that the

traditional Chinese ideal of maintaining harmony strongly influenced the basic social processes underpinning health care decision-making within China. Further work is needed to see if these findings also relate to other Asian countries (such as Japan, Korea).

However, no similar evidence on the role of the idea of maintaining harmony in health care decision-making was found in studies on participants from western backgrounds, further highlighting the strong influence of harmony as the core value of Chinese traditional culture (Chen and Starosta, 1997). Furthermore, little information on the idea of maintaining the whole body of a deceased individual was reported by other researchers in both western and eastern literature, perhaps because this idea seemed to be mainly held by Hui people who are only one of the 56 ethnic nationalities in China. In addition, no similar findings were identified in the literature on stroke care, indicating the need for further exploration.

Within the remaining levels of cultural influences identified in the current study, a few similar findings were reported by other researchers in the literature on stroke care as well as that in the wider context. These mainly included:

- The key part played by family in health care decision-making especially among Chinese (e.g. China, Hong Kong, Taiwan) and other Asian cultural contexts (e.g. Japanese, Korea) (Tang et al., 2006; Cong, 2004; Yap et al., 2004; Yun et al., 2004; Huang et al., 2003; Elwyn et al., 2002; Liang, 2002; Bowman and Singer, 2001; Ruhnke et al., 2000)

- Professionals', in particular doctors', reluctance to disclose negative information to patients (Weng et al., 2011; Elwyn et al., 2002; Ruhnke et al., 2000) which either facilitated or inhibited professionals' communication with patients or carers and their decision-making processes (Zhang et al., 2008; 2010; Smith et al., 2009; Fraenkel and McGraw, 2007b; Belcher et al., 2006; Health Care Commission, 2006; Proot et al., 2000a; 2000b; 2002; Walker and Dewar, 2001; Elwyn et al., 1999; Jewell, 1996)

- The influence of family patterns of decision-making style (Zhang et al., 2004; Proot et al., 2000a; 2000b; 2002; Bowman and Singer, 2001)

- The impact of patients' personal values or beliefs on their participation in decision-making (Ross et al., 2001; Arora and McHorney, 2000).

It's interesting that, in terms of the first two aspects, namely the family-oriented decision-making style and professionals' unwillingness to tell patients bad news which seemed to be closely linked to the desire to maintain harmony of mind, similar findings were only identified from studies within Chinese or other Asian cultural contexts. This seemed to suggest the strong influence of harmony-oriented and family-centred Confucian cultural tradition and social ethics on people's behaviours across different Asian countries. On the other hand, as for the remaining three issues namely the influence of team culture, family working patterns and personal beliefs, similar findings were likely to be identified from wider cultural contexts, in particular western literature.

Moreover, no evidence from other studies supported the current finding that regional cultural variations could determine who played a major role in decision-making, indicating that this difference was perhaps due to the special folk customs or local habits or traditions held and passed down from generation to generation by people living in a particular geographical area of China, such as Shantou city as reported by participants.

Equally important to making decisions were a variety of other influencing factors which were reported by the participants in the current study and briefly outlined below:

- Factors influencing initial help seeking and the choice of hospital:

    o Hospital reputation, distance between a patient's home and hospital, quality of the physical environment

- Medical/treatment related factors influencing decision-making during hospitalization:

    o Risk/costs, urgency of patient's condition, treatment effects

- Patient/carer related factors:

    o Level of education, personality, gender, profession, age of patient, carer's ability to pay, carer's perceived competence to make decisions, people's understanding about disease/stroke, the health insurance system,

and economic/financial conditions/circumstances

- Professional related factors:

  o Perceived experience and seniority of doctor, first impression about a doctor given to patient/carer, staff expertise or quality of service

- Trust:

  o Closely related to maintaining harmonious relationships and central to effective decision-making

  o Patients'/carers' trust in hospital, professionals, information, or TCM

  o Patients' trust in carers

  o Professionals' trust in patients/carers

Within both the area of stroke care and the wider context, studies focused on four areas, namely, patients' age, gender, education level, and patient'/carers' trust in professionals.

For example, other researchers also suggested that the younger the patient, the more likely they were to prefer to make decisions on their own or prefer a more active role in making decisions (Almborg et al., 2008; Chang et al., 2008; Deber et al., 2007; Menne and Whitlatch, 2007; Florin et al., 2006; Levinson et al., 2005; Henderson and Shum, 2003; O'Connor et al., 2003; Rosén et al., 2001; Arora and McHorney, 2000).

Although mixed findings regarding the preference of participation in decision-making among men and women were reported by other researchers (Andersson and Hansebo, 2009; Chang et al., 2008; Menne and Whitlatch, 2007; Kapral et al., 2006; Levinson et al., 2005; Arora and McHorney, 2000), the main findings in the current study were about the fact that men were more likely than women to use or draw on job-related knowledge (i.e. knowledge developed or gained from their daily working experiences or working lives) when making decisions with health professionals, and to view decision-making largely as a 'job'. However, there is limited understanding about the way men approach health care decision-making

activities in the literature, suggesting that further exploration is needed.

As for the impact of education level, the findings in the current study reinforced the positive influence of patients' higher education on their participation in making decisions. Other researchers also reported that patients with higher education levels are more willing to make decisions and play a more active role in decision-making (Almborg et al., 2008; Chang et al., 2008; Deber et al., 2007; Menne and Whitlatch, 2007; Levinson et al., 2005; Rosén et al., 2001; Arora and McHorney, 2000), while patients with lower education levels were more likely to be passive (Smith et al., 2009; O'Connor et al., 2003).

The role of patients' trust in professionals in their health care decision-making was also highlighted. The current findings and those reported in the literature were similar, suggesting that high levels of trust facilitated patient decision-making whereas a low level of trust inhibited it (Lown et al., 2009; Rydeman and Tornkvist, 2009; Sahlsten et al., 2009; Zhang et al., 2008; Fraenkel and McGraw, 2007b; Belcher et al., 2006).

This suggests that trust is as an essential component of relationships between different stakeholders during their health care encounters (Entwistle, 2004).

Types of knowledge used to inform decision-making and their sources

It was found that, in order to facilitate decision-making processes, patients and carers in the current study had a strong desire for health-related information and often drew on a wide variety of information sources and actively searched for and used information. These largely included:

- Specialised medical knowledge gained through communication with professionals
- Knowledge gained from mass media or training
- Knowledge gained from their own prior health care related experiences
- Knowledge gained from their working lives (e.g. men)
- Knowledge gained from their relatives/friends/colleagues/neighbours or other social networks
- Knowledge gained from other patients with stroke and carers sharing the same room/ward

In the literature, many studies suggested that patients and carers need access to good quality information in order to actively participate in decision-making and health care (e.g. Shepperd et al., 1999). They needed to be informed about all aspects of the disease and care at all stages of the patient journey (Rodgers et al., 2001), but often still had many unanswered questions (Hanger et al., 1998).

In order to satisfy their information needs, patients and carers tried to locate and obtain information from different sources or through different approaches which were largely similar to those used by the participants in the current study, such as consulting professionals (Lown et al., 2009; Larsson et al., 2007), accessing mass media (Zhang et al., 2010), referring to their own previous experiences in relation to health (Kelly-Powell, 1997) and seeking advice from other relatives, friends or colleagues (Takahashi et al., 2003).

The findings suggested that knowledge and information play an essential role in helping patients and carers actively participate in decision-making and feel more in control. Good information empowered them to effectively self-manage long-standing chronic conditions, have a good recovery and prevent another stroke, Therefore keeping patients and carers well informed is seen as essential to their well-being (RCP, 2008). It is also deemed to be extremely important that health professionals clearly identify and assess patients' and carers' information needs at different stages of their stroke career and use effective strategies to provide them with high quality and individualised information (Kerr et al., 2010).

The theory developed here has been a mid-range substantive theory exploring decision-making in acute stroke in China. Comparison with the wider literature has identified a number of similar ideas, albeit that the current study has expanded upon many of them suggesting the potential to elevate the theory to a more formal level. However there are a number of higher order concepts, some emerging from other GT studies, that may offer explanations for the similarities found and take debate to a higher level. Attention is turned to three of these below. These are: awareness contexts; partnership working and relational practices.

Awareness contexts

It seems particularly appropriate to start this discussion with the idea of awareness contexts, as these concepts emerged from the first ever GT study (Glaser and Strauss, 1965). These authors were studying the nature of death in acute hospitals

and the extent to which professionals, families and patients were all aware of the reality of the situation. Based on their study, Glaser and Strauss (1965) outlined four main types of awareness contexts of impending death. These were: closed awareness; suspected awareness; mutual pretence awareness; and open awareness, each of which remains relevant today, albeit in differing settings.

The awareness contexts were categorised into four main types largely depending on the 'knowledge' people had about the existence of a 'terminal condition' and their willingness to talk openly about this knowledge with others, including:

- Closed awareness – where some people (usually staff and family) were aware of the terminal diagnosis, and others (usually the dying person) were not aware, or a situation existed where everyone was aware of the diagnosis but some refused to acknowledge or discuss it.

- Suspected awareness – where some people were aware of the diagnosis (again usually staff/families), and others suspected it (usually the patient) and were actively engaged in trying to confirm their suspicions.

- Mutual pretence awareness – where everyone was aware of the diagnosis but this was not openly acknowledged and people 'pretended' they did not know.

- Open awareness – where everyone knew of the diagnosis and discussed it in an open and honest manner.

(Based upon Glaser and Strauss, 1965 and Hellström et al. 2005, p. 276).

It was argued that at the time (1960's) death was a 'taboo' subject and so professionals and families often worked hard to create and sustain a closed awareness context which kept the dying person largely unaware of the seriousness of their condition. In the Western world there is now generally a more open attitude towards death but this is not necessarily the case in other areas of health care and awareness contexts have been explored in a range of different situations such as care of patients with dementia (Hellström et al., 2005; Hutchinson et al., 1997), brain tumours (Salander and Spetz, 2002), brain injury (Yeates et al., 2007), and cancer (Carlander et al., 2011; Knight and Field, 1981). These have demonstrated how studies on differing health care issues can modify, and extend the original GT as new findings and understandings emerge, and how classic theory remains vivid

and pertinent to changes in structural or behavioural social processes (Andrews and Nathaniel, 2009).

In the context of the current study, the notion of awareness contexts helps to explain 'hiding' as a key social process used by professionals and family carers when making decisions about, rather than with, hospitalised stroke patients. One of the most important findings suggested that hiding behaviours, in particular, permanent hiding was used widely by carers and professionals in order to keep negative information or bad news from patients. This effectively created a 'closed awareness' context, the goal of which was to maintain the older person's peace of mind.

The study found that an additional but equally important motivation underlying doctors' hiding behaviours was to maintain a harmonious relationship with families and thereby avoid potential conflict.

As with Glaser and Strauss' original study, doctors and families expended considerable efforts to maintain their hiding behaviours and the result was that patients were excluded from the most serious and far reaching of decisions. Unlike the earlier American study, there was little evidence of suspicion awareness or of mutual pretence, with open awareness being confined largely to the younger or more highly educated stroke survivors. It may well be that so deeply ingrained is the need to maintain inner harmony that older people themselves do not wish to hear bad news and therefore make no real effort to find out. When an open awareness context emerged unexpectedly the consequences in the current study were largely negative and included a disrupted happy mood, less perceived potential for a good recovery, disrupted relationships between the carer and doctors, and the carer's unhappiness and distrust towards doctors.

The study suggested situations where carers and professionals fully disclosed information to patients so that everyone could be involved in an open discussion were confined largely to decisions about minor health problems, diet, physical activity or similar issues.

The above scenarios describe what might be termed 'permanent closed awareness contexts' but there were also instances when what might be termed 'temporary closed awareness contexts' were created and these were more commonplace and created by all parties, again with the primary intention of 'keeping the peace'.

Examples included:

- Patients temporarily hid information about their condition and hospital treatment from:

  - Their older spouse to prevent them from suffering fears or anxiety;

  - Their children due to their reluctance to bother them.

- Carers, especially spouses, temporarily hid information regarding the patient's situation from their adult children due to their reluctance to bother them.

These findings suggested that there were two types of closed awareness contexts, namely permanent and temporary closed awareness contexts, with the latter being more open over time.

The idea of awareness contexts provides an important historical link between the context of caring for people dying in the hospital and decision-making in stroke care in the current study, but in a differing cultural context and several decades later. In their original work Glaser and Strauss (1965) noted that the main factors contributing to the creation and maintenance of a closed awareness context included doctors' ordinary practice of not telling patients they were dying based on their professional belief that patients really did not wish to know, and families' willingness to guard the secret. In the current study, although carers and professionals also aimed at keeping negative information secret rather than disclosing it to patients, their motivation seemed to be more complex, given the fact that their hiding behaviours were strongly shaped by the Chinese cultural tradition of maintaining harmony in both people's minds and interpersonal relationships. This reflected the key difference between the findings in the current study and those in the original work.

Therefore, the current study extends the reach and dimensions of the original awareness context work by adding the idea of permanent and temporary closed awareness contexts having differing temporal dimensions and consequences.

Whether the ideal of 'maintaining harmony' remains as pervasive and influential in the future remains to be seen. China is becoming more Westernised and traditional cultural values are being eroded. However, for the time being at least Chinese

professionals need to have a clear understanding of awareness context theory, and be more aware of the need to carry out a comprehensive assessment of patients' preferences or desires for different awareness contexts.

A better understanding of the way in which stroke patients, their family carers and professionals make health care decisions and the idea of awareness contexts will potentially sensitise professionals to important issues that surround stroke care and help them make better decisions with patients and carers and provide a quality service. Thus, almost 50 years after it was first developed, the idea of awareness contexts continues to offer practical suggestions for improving the quality of patient care (Andrews and Nathaniel, 2009).

Attention is now turned to the concept of partnership working, a theme that is prevalent in debates about participation in health care in the west.

Partnership working

Courtney et al. (1996, p. 181) define partnership as "the negotiated sharing of power between health professionals and individual, family and/or community partners…(who) agree to be involved as active participants in the process of mutually determining goals and actions that promote health and well-being". For several decades, partnerships between patients, families and professionals have been recommended practice in effective service provision across various disciplines in health care (Hook, 2006).

Many authors identify the importance of patient, family and professional partnerships in motivating and facilitating patients and families toward active participation in shared and informed decision-making and health care, and improving patients' quality of life. Such partnerships have been actively promoted in public policy, research, and legislation (American Nurses Association, 2010; Lown et al., 2009; Sahlsten et al., 2009; Hook, 2006; Brereton and Nolan, 2003; Fox, 2003; Department of Health, 2001b).

In stroke, partnership working has been promoted as the antidote to traditionally paternalistic medical practices (Lown et al., 2009; Sahlsten et al., 2009; Fraenkel and McGraw, 2007b; Larsson et al., 2007; Nolan et al., 2004; Nolan et al., 2003a; Brereton and Nolan, 2002; 2003; DoH, 2001b; Wilson et al., 1998; Trojan and Youge, 1993). However, partnership working is rarely mentioned or reported in

Chinese and other Asian contexts, suggesting possible cultural differences in what is seen as 'best practice'.

Despite its active promotion, partnership working has been characterised as an immature concept requiring further development and investigation (Hook, 2006; Gallant et al., 2002). In the context of this study, I will consider how the basic social processes identified are consistent with concepts such as partnership working in the context of treatment related decision-making by drawing on the seminal works on partnership in making medical decisions (Charles et al., 1999a; Coulter, 1999) and partnership as a core concept within the context of professional–patient/carer relationships (Hook, 2006; Gallant et al., 2002).

In their seminal work on the meaning of partnership in medical decision-making, Charles et al. (1999a) argue that there are basically three treatment decision-making models namely the paternalistic, the shared, and the informed. These depend on the nature of the information exchange (e.g. the flow, direction, type and amount of information exchanged), discussion of treatment preferences, and who decides on the treatment to be implemented. They suggest that in most clinical consultations the interaction of these factors defines the dominant partnership model that exists. These are outlined below.

The paternalistic model

The characteristics of this model are well known and described as the traditional 'professional knows best'/passive patient model (Hook, 2006), in which there is no sharing of decision-making activities or power so, by definition, a doctor-patient partnership does not exist. In the current study, there seemed to be two types of situations in which paternalistic decision-making style was used without any application of partnership working.

The first was characterized by the frequent use of hiding by both doctors and carers to prevent patients from knowing negative information or bad news mainly in order to maintain harmony in its various forms. The primary difference between the model described here and that presented by Charles et al. (1999a) is that carers were complicit in my study and played an active role in the whole process. Due to the extensive use of hiding, patients were effectively excluded from receiving health related information, discussion about alternatives and making decisions about what treatment to implement. Under these circumstances, decisions were usually made

by doctors or carers depending on whether a potential risk or cost was involved. These behaviours can be considered consistent with the characteristics of paternalistic treatment model devoid of partnership working between doctors or carers and stroke patients (Charles et al., 1999a).

The other situation where paternalistic rather than a partnership working style was dominant was decision-making regarding routine, risk free and cost neutral treatments. In these circumstances, doctors rarely involved patients or carers in decisions but rather made such decisions and 'then' informed patients/carers after the decision had been made. Therefore, in these instances doctors took absolute authority, and played a dominant role in decision-making without viewing patients and carers as partners.

The informed model

The main role of health professionals in making decisions that involved high risk or major costs was in providing information or explanation primarily to carers, answering their questions and offering suggestions or advice. This suggested an informed model of decision-making with a loose partnership between the doctor and carer based on a strict division of responsibility (Charles et al., 1999a).

Here there was basically a one way information exchange from doctor to carer whereby the doctor usually initiated communication and used informing and advising processes to provide the carer with information on relevant treatment options and their benefits and risks, sufficient to enable the carer to make an informed treatment decision. Meanwhile, the carer might use searching processes to ask questions and elicit information from the doctor, or if an element of trust was missing would also employ checking behaviours. Once again the main motivation was to maintain harmonious or peaceful interpersonal relationships, and avoid potential conflict. By definition, this was not a genuine partnership.

The study suggested that this way of working was far more likely to occur between doctors and carers, and less likely to occur between doctors and patients unless patients had higher education levels or adopted an optimistic attitude towards their lives. According to several doctors, they were much more likely to provide information involving risk or cost issues to such patients, and this allowed them to be much more involved in the decision-making process.

The shared model

In contrast to the informed decision-making model, the essential characteristic of the shared decision-making model is its interactional nature in that the doctor and patient or carer have a two way information exchange process, full discussion, and jointly agree a way forward (Charles et al., 1999b; Charles et al., 1997). During the exchange of information, both parties openly discuss preferences and reach an agreement on the decision to implement. This form of partnership working is consistent with the definition given by Courtney et al. (1996) with its power sharing nature and an equal relationship.

Based on the findings of the current study, this form of partnership working was relatively rare. The types of decisions that needed to be made using this model also involving either risk or cost but there was a more two way information exchange in that doctors would use not only informing and advising but also searching processes to elicit information from carers about the patients' condition, the carers' and perhaps the patients' preferences, needs, and concerns. Carers would also use both informing and searching processes in a more dynamic interaction with doctors. Therefore, unlike the informed decision-making style, here both parties demonstrated seeking and sharing behaviours when making decisions in order to try and achieve consensus.

As will be seen from the above, irrespective of the model adopted it is the carer rather than that patient that has the primary interaction with the professional, usually the doctor. This highlights the limits of partnership working in the context of current practice in China. However, once again whether this pattern will be maintained for the next generation of older people who will be much more used to playing a major role in decisions in general remains to be seen. Therefore, the paternalistic style is likely to be increasingly challenged as China becomes more and more open to the Western ideas and it is probable that in decades to come older couples will be less willing for their children or professionals to take over the decision-making process. Chinese professionals as well as lay people all need to have awareness of these potential changes in people's ideas.

In addition to changing cultural influences, other factors at an individual level also need to be taken into consideration. Despite the Western ideal of partnership, several studies show that not all patients favour a partnership model (Levinson et al., 2005; Coulter, 1999) and there is evidence to suggest that some patients do not

want to be actively involved in decisions about their care (Almborg et al., 2008; Mangset et al., 2008; Deber et al., 2007; Huby et al., 2007; Belcher et al., 2006; Yap et al., 2004; Huang et al., 2003). Moreover, as levels of frailty, especially cognitive, rise not all older people may be able to take an active role. Clearly this is an area that is likely to undergo considerable change in the future.

Attention is now turned to the concept of relational practices.

Relational practices

As will be fully apparent by now, the most important influence on decision-making to emerge from this study was the nature of the interpersonal dynamics between older people with stroke, family carers and professionals. Several basic social processes were identified, primarily hiding, seeking and sharing. It is suggested here that these are best seen as forms of 'relational practices'. Ideas of relational practices and related concepts were suggested by Liaschenko (1997) who highlighted the importance of what she termed 'relational knowledge' in health care practice. It is recognsied that in order to deliver high quality care professionals need to apply differing forms of knowledge to their daily work (Benner et al., 1996; Tanner et al., 1996).

One of the most influential models of such knowledge was developed by Liaschenko and her colleagues (Stein-Parbury and Liaschenko, 2007; Liaschenko and Fisher, 1999; Liaschenko, 1997), who identified three broad types of knowledge that can be used to inform health care decision-making. These were:

- Case knowledge comprising biomedical, scientifically derived general knowledge, e.g. pathophysiology, disease processes, pharmacology, and other therapeutic protocols, which is independent of a particular individual or context and largely the domain of professionals, especially doctors.

- Patient knowledge is much more contextual and defines an individual's response to a disease and its treatments, and is used primarily by nurses. It can be seen as the human application of case knowledge.

- Person knowledge is altogether more individual and holistic and requires an appreciation of the patient as a person with a unique biography. Such knowledge alerts us to what it is like to and what values and goals inform such a

life. It is captured by Stein-Parbury and Liaschenko (2007, p. 473) as follows "to know a patient as a person is to know what the recipient of care knows, what matters to the recipient and why".

Liaschenko and Fisher (1999) argue that it is the nurse who uses his/her relational knowledge and relational practice to create a bridge between case knowledge, patient knowledge and person knowledge in order to make the links and connections needed for good health care delivery.

Others have since then taken these concepts and expanded them to fields other than nursing and have provided the following broader definition of relational practice as those activities "necessary to develop and sustain interpersonal relationships" (within health care) based on an understanding of an individual's circumstances and their contexts (Parker, 2002, p. 277). Such practices are seen as increasingly essential to the delivery of high quality care and there has been much recent work to expand our understanding of the types of activity that constitute relational practice and what its impact is (Patterson et al., 2011; Petersson, 2009; Williams et al., 2009; Davies et al., 2007; Dewar, 2007; McGilton et al., 2003).

For example, Williams et al. (2009) used discharge planning as a case example and argued that in order to improve the care of older people in acute settings, far greater recognition must be given to the importance of 'relational practice' as the basis for high quality care, and more emphasis must be put on the nature and quality of relationships between professionals, older people and their carers. In an extensive study on culture change in acute care services for older people in hospital, Patterson et al. (2011) suggested that relational practices should be recognised as a core professional skill that needs to be valued, promoted and supported.

Parker (2002) argued that for relational practice to flourish the following factors need to be considered:

- Accessibility – professionals need to be available to patients and carers when needed.

- Boundary management – professionals need to construct emotional connections with patients and carers during their interaction but also avoid becoming overwhelmed.

- Connection – Professionals need to have engagement, empathy and emotional authenticity.

- Collaboration – professionals and patients/carers need to actively share information and all be engaged in relational work.

- Continuity – the ability to relate and bring past and present experiences, interactions and knowledge.

The above resonate in several respects with the findings described in this thesis and it is suggested here that hiding, seeking and sharing all constitute differing forms of relational practice that largely shape the interactions between parties and exert a significant impact on health care decision-making. For example, many aspects of hiding can be seen as 'boundary management' strategies as they help to maintain harmony and also reduce the potential for deflating the patient's mood or of conflict between professionals and carers. Seeking and sharing activities represent examples of differing forms of collaboration and connection which in a number of cases help to ensure continuity. However, activities such as hiding also potentially serve to limit the extent to which accessibility and connection are experienced, especially for patients.

More work is needed to explore how these relational practices are manifest in different settings and contexts in order that their full influence is better understood.

If we adopt the view of Liashenko and her colleagues (Stein-Parbury and Liaschenko, 2007; Liaschenko and Fisher, 1999), such relational practices (e.g. seeking, sharing, and hiding) are actually forms of 'knowledge' that help to shape health care and as such need to become part of the professional repertoire of skills that recognize both the good uses to which such knowledge can be put, but also the potentially negative consequences of practices such as hiding.

Certainly the findings of this study provide probably the first insights into how, largely implicit, relational practices impact on decision-making. Future work can make these practices more explicit so that they can be promoted or countered depending on the circumstances and context.

Another way in which this study has furthered thinking with respect to relational practices is the contribution made by carers. To date the literature on relational

practice has been almost exclusively professional, mainly nursing, whereby relational knowledge and practice is used by nurses to 'bridge' other forms of knowledge and to 'broker' relationships between other professionals (mostly doctors) and patients/carers (Williams 2001; Williams et al., 2009). However, it was quite clear in this study that carers played a highly significant, indeed often the dominant, role in decision-making and in so doing engaged in multiple forms of relational practice and drew upon diverse forms of relational knowledge. As noted earlier this may have been due largely to the traditional decision-making role accorded the family in Chinese culture (Cong, 2004) and their 24 hour presence on the wards. However, such considerations have much wider relevance as welfare systems throughout the world increasingly rely on creating partnerships with family carers (Nolan et al., 2003a). Further exploration of the types of relational practices described here can hopefully lead to a better understanding of how to work in partnerships that also more fully include the older person.

The above discussion has considered the findings of this study in relation to the wider related concepts found in the literature of awareness contexts, partnership working and relational practice. Areas of resonance have been explored together with ways in which the study has contributed to a fuller and more rounded appreciation of these ideas, which would benefit from yet further exploration. In so doing it has hopefully demonstrated the contribution of the study beyond the immediate questions that it sought to address. The thesis concludes with a consideration of the implications of the work.

Implications of the Current Study

Implications for practice

Professionals

As noted above the study advances understanding of the types of relational practices that, often implicitly, shape decision-making following stroke in mainland China. Illuminating these practices makes them more explicit and as such professionals may now use them in a more informed way. Given the importance attached to maintaining harmony in its various guises it may be neither possible nor desirable to fully involve older people in all decisions, but awareness of the full extent of their exclusion may help to alert professionals of the need for a more complete, if still discrete exploration of their wishes in this regard.

Whatever developments occur over time it seems that for the immediate future that carers will remain significant players. In order to help family carers make effective decisions for their older relatives, professionals need to actively communicate with them to assess their preferences for participation in making decisions and their information needs. Subsequently, professionals need to actively use various seeking and sharing strategies, not only to provide carers with the necessary information, but also to gain information about the patient's condition, as well as patients' and carers' needs, concerns and experiences. The explicit fostering of close interactions between professionals and carers from the outset can establish harmonious relationships between the two parties, which in return will further improve the quality of decisions that are made and lessen the potential for conflict.

The current study identified a wide range of factors influencing decision-making processes (e.g. age, educational level, etc), and a fuller understanding of these influences will enable professionals to provide better support to patients and carers and assist them in making effective decisions that are consistent with their needs and wishes.

Patients and carers

The findings provide useful information that patients and carers may be able to use to better understand health care decision-making, more closely and successfully work with professionals, and make decisions more effectively. For example, patients and carers could not only actively seek information and support from professionals, but also more openly express their own needs, concerns, opinions, experiences and share information about the patient's condition with professionals. Such active two way interactions between them and professionals may potentially enable a more effective decision to be made so that optimal care is provided to patients.

Since family carers play a key role in accompanying and caring for patients during their hospital stay, they could make greater efforts to act as a conduit for information exchange and provide an important link between patients and professionals and facilitate patients' participation. When making decisions involving potential risk or cost or other negative information, carers could also work together with professionals to explore patients' particular needs, preferences, or concerns, and make appropriate judgements about the extent to which they

involve patients within information provision and decision-making, and whether to share or hide certain types of information. The above strategies can help family carers to maintain harmonious relationships with patients and professionals, and keep patients' peace of mind.

Understanding of the factors influencing decision-making is also helpful for patients and carers to make effective decisions. For example, they could more closely work and actively communicate with professionals in order to establish a harmonious relationship in which both parties have mutual trust, understanding and respect for each other. Patients and carers could seek the information or knowledge required to make decisions from professionals, and be encouraged to be careful about the quality of information when seeking information from other types of sources.

Therefore the study findings are considered useful and able to potentially encourage positive changes in the practice. However, in order for the findings to enable and create changes to improve the decision-making experiences of patients and carers, actions are required at different levels. For example, at an organisational level e.g. in a unit or a hospital, managers need to ensure that the policy and practical guidelines encourage professionals to work closely with patients and carers in health care decision-making activities and meet their specific needs, and advocate the establishment of harmonious interpersonal relationships based on mutual trust and respect between staff members, patients and carers. Achieving this requires effective support mechanisms for staff, including effective leadership, appropriate training and clinical supervision.

The development of the current GT and the identification of core categories have considerable potential to inform decision-making in the context of stroke and to be applied in clinical practice.

Whilst the above changes are highly desirable and clearly supported by the study findings the challenges of implementing change must be acknowledged. This will require changes to culture, not only within health care but potentially also to long held beliefs within Chinese society. As China becomes more exposed to Western culture concepts such as participation and involvement may become more readily accepted. Indeed it seems unlikely that future generations of Chinese Elders brought up with ready access to outside influences via social media and other

sources will be happy accept the largely passive role adopted by the participants in this study. Such developments are likely to occur naturally overtime.

However, in the meantime there is much that could be done to begin the process of change now, by considering new approaches to education and policy. Some suggestions are presented below.

Implications for education

If the findings of this study are to have maximum impact strategies need to be devised to enhance equal access to the results that ensure that they are widely available and conceptually accessible to a broad range of stakeholders. For example, in order for policy makers, managers and professionals to get access to the findings, they need to be published in academic journals, books, and disseminated at research conferences.

In order to increase lay people's (e.g. patients and family carers) access to the study findings a variety of different approaches can be taken, these could include:

- Placing them on stroke related websites that are widely accessible to all e.g. professionals, people with stroke, family carers, or lay people who are interested in stroke related topics;

- Publishing them in popular journals or magazines;

- Creating pamphlets for use in local hospitals;

- Distributing them to patients and carers in a workshop or small training sessions given by professionals in local hospitals;

- Disseminated through other types of mass media, e.g. TV, radio, newspaper.

The language used must be taken into consideration. It is particularly important for older patients with stroke that written information is in an appropriate format with large text, suitable colours, and 'easy to read and understand' language (Blanck and Marshall, 2011; Scottish Intercollegiate Guidelines Network, 2010).

Implications for professional health care education

In terms of the implication of the study for health care education, the findings can be used in the training of professionals (e.g. doctors, nurses and other staff). An understanding of health care decision-making in stroke care can provide educators with insights about the importance of developing students' abilities to work as effectively as possible with patients and family carers.

The current study offers guidance for the content of future courses and curriculae that focus on the principles and practice of partnership working and the range of skills required. Such education needs to target practitioners in their initial training and those who are already qualified. This needs to focus explicitly on the relational practices that enhance decision-making, and these need to be recognized as core professional skills.

Implications for education for lay people

The study findings have the potential to be used to produce information, advice and guidance for patients and carers that enable them to work more effectively with professionals. They also suggest areas where greater knowledge is needed. Two stand out in particular.

One is about increasing people's understanding of the current health insurance policy system through public health education. The study suggested that the issue of cost and the understanding of health insurance principles and regulations played a key role in influencing patients' or carers' choices on important issues relating to examination, treatment and other types of health care services. Therefore, an enhanced awareness of insurance policy can potentially assist patients and carers in making more appropriate health care decisions.

The other aim should be to improve people's level of health literacy through public education. The current study suggested that patients' and carers' understanding about disease and health related issues figured prominently in their decision-making, not only during their acute hospital stay, but also at the onset of stroke, after discharge back home, and during the rehabilitation or recovery phase. With better basic health literacy people can better manage their condition throughout the entire stroke journey and potentially prevent the occurrence of the second stroke.

Implications for policy

The study can also help to inform the development of policy by the Ministry of Health and other government organizations or regulatory bodies in China in order to improve health care decision-making practice. The findings can help encourage different levels of government to:

- Re-think the health insurance system to reduce the economic impact of stroke on patients, carers and society through:

    o Expanding health insurance coverage to health care services for older people;

    o Providing preferential rates for health insurance for older people.

- Develop policy which implements a health education campaign to increase people's level of health literacy and understanding about health insurance.

- Developing policy and modifying current guidelines regarding stroke care so that they stress:

    o Professionals' duty in relation to quality health information provision to patients and carers, thereby enabling them to make better health care decisions;

    o Patients' and carers' legal rights in relation to informed consent and participation in health care decision-making and services.

- Developing policy which advocates:

    o Active collaboration between professionals, patients and carers in making health care decisions.

Implications for further research

The findings in this study have suggested some important areas for further investigation, both within the area of stroke care in more diverse contexts, and in other substantive areas relating to other conditions. Potential studies include:

- Exploring health care decision-making in the context of aphasia, serious stroke, stroke with other complications such as cognitive impairments or mental illness, e.g. depression;

- Exploring health care decision-making in the context of stroke in more diverse settings, for instance, selecting samples:

  o From different hospitals within the same city to compare findings;

  o Across different cities or regions of China to compare findings;

- Using ethnography to describe Chinese patients', carers' and professionals' values, beliefs and experiences of day-to-day decision-making practice on stroke wards within a Chinese cultural context;

- Exploring health care decision-making in the context of other conditions such as cancer, heart disease, diabetes, or dementia within China;

- Extending the study to other Asian populations living in differing countries.

Although the study was undertaken in an acute care hospital in a contemporary Chinese context, it identified a wide range of decision-making behaviours that may be equally relevant in different contexts, as noted above. This merits further study on a diverse range of issues.

Conclusion

This study aimed to explore decision-making processes between people with stroke, their family carers and professionals in an acute care context in China. It is the first of its kind to adopt a constructivist GT methodology to explore this important topic area.

The findings of this study provide evidence of the specific social processes which patients, carers and professionals employ when making decisions around stroke and offer new insights, particularly into the role of culture in health care decision-making. These results could contribute to the development of practical, educational and policy initiatives to enhance decision-making practices, improve quality of

stroke care and the quality of life of life of stroke patients and their carers.

In addition to elaborating upon the core processes involved in decision-making, the study also identified a range of important contextual and background factors that influence people's decision-making including: the people who are involved; types of decisions that are made; types of knowledge that are used; environmental factors; medical/treatment related factors; patient-, carer- and professional-related factors; and culture and trust.

All these contribute new knowledge about decision-making behaviours in the area of stroke care within a specific cultural context. The study suggests the need for a number of changes and improvements in stroke care practice, education, policy, and research areas. The present study is therefore significant as it contributes to an increased understanding of the dynamics of health care decision-making among older patients with stroke, family carers and professionals within a Chinese cultural context. Hopefully, it will also have wider relevance and currency in differing settings and in relation to differing conditions. A good GT needs to 'work' and be applicable in the real world. This will be the ultimate test of the usefulness of this particular piece of work.