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

Submitted for the degree of
Doctor of Philosophy (Ph.D.)

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June 2013

Volume 2
References


Blanck, A. W. and Marshall, C. (2011) Patient education materials from the


Brummel-Smith, K. (1994) Management of poststroke patient. *Hospital Practice*


Charmaz, K. and Mitchell, R. G. (2001) An invitation to grounded theory in


Glaser, Barney G. and Strauss, Anselm L. (1965) *Awareness of Dying*. Chicago,
Aldine Publishing Company.


in caring. *Disability and Rehabilitation*, 29(2), 111-121.


Petersson, P. (2009) Telling stories from everyday practice, an opportunity to see a bigger picture: a participatory action research project about developing discharge planning. Health and Social Care in the Community, 17(6), 548-556.


Porter, S. (1991) A participant observation study of power relations between nurses


263


and Winston.


Tuckett, D., Boulton, M., Olson, C. and Williams, A. (1985) *Meetings between*


Williams, S., Nolan, M. and Keady, J. (2009) Relational practice as the key to


Zhang, Z. (2000) The comparison of women’s status between Han and Zhuang
nationality in traditional society. *Journal of Guanxi Normal University*, 1, 152-156.


Appendix 1 Historical Development of Social Health Insurance System in China

Rural health insurance
China’s health insurance for the rural population was set up in 1955 and named cooperative rural health insurance in Henan province. It then started to be carried out all over the country, grew quickly and reached a peak in the mid-1970s when 90% of the rural population were covered (Yang et al., 2010). Under the rural cooperative health insurance scheme, the financing of health care relied on the fund from three sources, including premiums (0.5 to 2% of a peasant’s family annual income), collective welfare fund (part of income from collective agricultural production or rural enterprises), and subsidies from higher-level government organisations (Liu, 2004).

However, since the 1980s, China has transformed itself from central planning towards market economy. In rural areas, the transition from agricultural collectives to the so-called ‘household responsibility system’ weakened the financial capability of agricultural collective economy system to support the rural cooperative health insurance. So the cooperative movement faded in the following years, and in the early 1980s rural cooperative health insurance collapsed in the majority of rural communities, and the coverage in the late 1990s was less than 8% of the rural population, causing growing equity problems in the financing of and access to health care among rural residents (Liu, 2004; Lennart et al., 1996).

Urban health insurance
The country’s social health insurance system for urban citizens was established in 1952. Historically, it was mainly consisted of two government systems – the Labour Insurance Scheme (LIS) and Government (employee) Insurance System (GIS). LIS covered medical costs for the current and retired workers in the state owned enterprises as well as their dependents. It would provide a range of benefits, including outpatient and inpatient medical care, and bear all expenses of medicine, medical treatment, and hospitalisation. GIS covered medical costs for the employees in the government and state institutions (Yang et al., 2010; Xu et al., 2007).

Although the two insurance systems had played an important part in providing Chinese urban working population with health protection and making great contribution to the economic development and social stability, they also resulted in the rapid health care cost inflation and inefficient resource allocation. For example, beneficiaries could receive comprehensive benefits without taking any financial
responsibility for their consumption of the health services, and therefore might not actively seek the most cost-effective health care. Meanwhile, when seeking medical help, these beneficiaries often went to public hospitals, where their health care expenses were usually reimbursed based on a government-set fee-for-service system, which increased the possibility of over-providing services by hospitals (Yang et al., 2010; Liu, 2002).

Other major problems with GIS and LIS include (1) the lack of risk pooling across both local governments and enterprises, which may lead to the inability to reimburse the employee’s medical costs, or may impose a heavy financial burden on both governments and enterprises; (2) the rapid surge of the prices of medical services and medications which makes the health care services become unaffordable for both urban and rural populations, and some people even have to sell their properties or borrow money to pay for their health care expenditures (Liu, 2002; Liu et al., 1996); (3) the inequality of health insurance coverage; and (4) the lack of adequate health insurance among an increasing number of urban residents (Yang et al., 2010).

The above problems, together with other factors such as the increasing number of beneficiaries joining in both schemes and the ageing of beneficiaries, highlighted the need and urgency for China’s insurance system reforms (Jiang et al., 2010; Liu and Hsiao, 1995).
### Appendix 2 Example of Literature Search Strategy

**SAMPLE SEARCH STRATEGY IN Ovid MEDLINE**

<table>
<thead>
<tr>
<th>Step</th>
<th>Search term</th>
<th>Number of articles retrieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>*decision making/ or *choice behaviour/ or *consensus/ or *negotiating/</td>
<td>35831</td>
</tr>
<tr>
<td>2</td>
<td>limit 1 to (english language and yr=&quot;1980 - 2010&quot;)</td>
<td>27434</td>
</tr>
<tr>
<td>3</td>
<td>*Patients/</td>
<td>9171</td>
</tr>
<tr>
<td>4</td>
<td>limit 3 to (english language and yr=&quot;1980 - 2010&quot;)</td>
<td>5492</td>
</tr>
<tr>
<td>5</td>
<td>*Family/</td>
<td>24729</td>
</tr>
<tr>
<td>6</td>
<td>limit 5 to (english language and yr=&quot;1980 - 2010&quot;)</td>
<td>17284</td>
</tr>
<tr>
<td>7</td>
<td>*Caregivers/</td>
<td>12481</td>
</tr>
<tr>
<td>8</td>
<td>limit 7 to (english language and yr=&quot;1980 - 2010&quot;)</td>
<td>9756</td>
</tr>
<tr>
<td>9</td>
<td>*Patient Participation/</td>
<td>8421</td>
</tr>
<tr>
<td>10</td>
<td>limit 9 to (english language and yr=&quot;1980 - 2010&quot;)</td>
<td>6809</td>
</tr>
<tr>
<td>11</td>
<td>*Health/</td>
<td>8356</td>
</tr>
<tr>
<td>12</td>
<td>limit 11 to (english language and yr=&quot;1980 - 2010&quot;)</td>
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<tr>
<td>13</td>
<td>2 and 4</td>
<td>197</td>
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<td>14</td>
<td>2 and 6</td>
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<td>4 and 10</td>
<td>70</td>
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<td>17</td>
<td>6 and 10</td>
<td>99</td>
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<tr>
<td>24</td>
<td>12 and 18</td>
<td>0</td>
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<tr>
<td>25</td>
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<td>86554</td>
</tr>
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<td>26</td>
<td>limit 6 to (english language and yr=&quot;1980 - 2010&quot;)</td>
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<td>27</td>
<td>brain ischemia/ or &quot;intracranial embolism and thrombosis&quot;/ or intracranial haemorrhages/ or stroke/ or brain infarction/</td>
<td>86169</td>
</tr>
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<td>29</td>
<td>26 and 28</td>
<td>233</td>
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</table>
## Appendix 3 Characteristics of Studies on Health Care Decision-Making (n=20)

<table>
<thead>
<tr>
<th>Author, year of publication, country</th>
<th>Aim(s)</th>
<th>Sample (age, gender, ethnicity) and setting</th>
<th>Design</th>
<th>Data collection and analysis</th>
<th>Rigour</th>
<th>Results</th>
<th>Summary of major limitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arora and McHorney (2000) the US</td>
<td>To identify the determinants of patient preferences for participation in medical decision making (DM).</td>
<td>2197 chronically ill patients with hypertension, diabetes, myocardial infarction, congestive heart failure, and depression. (42.2% men and 57.8% women; mean age 57.2±14.6; 20.4% non-white and 79.6% white)</td>
<td>Cross-sectional observational qualitative study</td>
<td>Participation preference, socio-demographics, diag., severity, coping, social support, health distress or value, will to function, lifestyle analysed statistically.</td>
<td>Cronbach's alpha and skewness were calculated.</td>
<td>69% of the patients preferred a passive role—towards medical decisions to physicians. Patients who were younger, female, had more education, less severe illness, active coping style, clinical depression, and placed lower value on health preferred more active participation.</td>
<td>Single-item dependent variable measure is less reliable than multi-item scale, and is only measured once.</td>
</tr>
<tr>
<td>Biley (1992) the UK</td>
<td>To discover how patients feel about participating in DM about nursing care.</td>
<td>4 male and 4 female informants who had undergone surgical procedures under anaesthesia, aged between 21 and 75.</td>
<td>Cross-sectional qualitative study using modified grounded theory method</td>
<td>Unstructured, open-ended interviews and qualitative data analysis.</td>
<td>Not reported</td>
<td>1st category 'If I am well enough' describes the states of 'Being too ill' to be involved in DM to 'Being well' which allows greater involvement. Level of participation depended on how well or physically fit they were. 2nd category 'If I know enough' describes situations that, first, 'Nurse knows best', where technical knowledge is required, and pts don't have enough information and prefer passive role; secondly, less technical matters where pts don't have enough info. and require more info. but still prefer to be passive; finally, 'I know best', where pts have enough info., and prefer to be actively involved in 'non-technical' areas, e.g., ADL. 3rd category 'If I can' describes organizational constraints/freedom that restrict/encourage participation. They had to fit in with organizational routine and had less choice on ADL. Or they were able to have some needs/desires met in ADL. Data were not structured. Strategies for ensuring trustworthiness of data were not known.</td>
<td>Sample size was small, there was no structured sampling plan, and data saturation was not achieved.</td>
</tr>
<tr>
<td>Deber et al. (2007) Canada</td>
<td>To examine the role patients would prefer in making treatment decisions across multiple clinical settings.</td>
<td>2754 patients with breast cancer, prostate disease, fractures, contiveness, orthopaedic, rheumatology, multiple sclerosis, HIV/AIDS, infertility, benign prostatic hyperplasia, cardiac disease, and healthy nursing students (mean age 52.5, age range 16-88, male 60.2%).</td>
<td>Cross-sectional quantitative study</td>
<td>Data was collected by survey or interview using Problem-Solving DM scale with one or both of Current Health Condition and Chest Pain vignettes, and was analyzed statistically.</td>
<td>Not reported</td>
<td>Few respondents preferred an autonomous role (1.2% current health condition; 0.7% chest pain). Most preferred shared DM (77.8% current health condition; 65.1% chest pain) or a passive role (20.3% current health condition; 34.1% chest pain). Greater familiarity with a clinical condition increases desire for a shared role (as opposed to a passive role). Preferences for passive (as opposed to shared) roles varied across settings. Older and less educated individuals were most likely to prefer passive roles (as opposed to shared roles).</td>
<td>Secondary analysis. No information about validity and reliability testing.</td>
</tr>
<tr>
<td>Elwyn et al. (1999) the UK</td>
<td>To explore the views of general practice registrars about</td>
<td>A purposive sample of 39 general practice registrars and 8 course organisers</td>
<td>Cross-sectional qualitative</td>
<td>Doctors conducted and observed the consultations with</td>
<td>Not reported</td>
<td>All participants considered ‘shared DM’ as novel. Some thought it was unrealistic, others were more receptive to it and its potential benefits. Barriers to sharing DM: lack of reliable information, reluctance to share</td>
<td>The use of simulated patients didn’t reflect</td>
</tr>
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</table>
involving patients in decisions, and to assess the feasibility of using shared DM model by means of simulated general practice consultations.

Florin et al. (2006) Sweden
To compare the degree of concordance between pts and RNs' perceptions of pts' preferences for participation in DM, and to compare patients' experienced actual level of participation with their preferred participatory role.

A convenient and consecutive sample of 80 nurse-patient dyads on an infectious disease ward (43 men and 37 women, mean age 59±6.5, age range 23–84), 35 RNs had a median age of 31.

Longitudinal comparative quantitative study. Study simulated patients. Then focus groups were conducted to explore their views on involving patients in decisions. Content analysis. A modified Control Preference Scale was used for participants to state preference and perception. A follow-up self-reporting questionnaire was used to explore pts' actual roles. Statistical analysis was used. Not reported

Patients most often preferred adopting a passive role (61%, n=46). No differences were found with regard to gender, but younger patients (<61 years) preferred being more active. Regarding needs of nursing and physical needs, patients living together with someone preferred a more passive role compared with patients living alone.

A majority of the RNs perceived their patients preferred a higher degree of participation than did the patients. 1/3 of pts perceived that their DM role cohered with their preferred role, or were more passive, or more active than preferred. Pts actually experienced a more passive role than preferred concerning needs on communication, breathing and pain when compared with RNs' inference. Pts actually experienced a more passive role than preferred concerning needs on communication, breathing and pain, but a more active role for needs in activity and emotions/roles.

DM was an ongoing process of multiple decisions over time related to diverse domains. Patients’ preferences might change over time. DM was performed within an extended social context. Decisions were often distinct from those traditionally studied, e.g., choice of physicians, whether to accept physicians' recommendations were more often than choice of treatment/exam.

Some pts highly valued physicians' recommendations. But others felt that physicians' recommendation limited their participation.

Five elements were essential to enable patient participation: 1. Patient knowledge: being adequately informed. 2. Explicit encouragement of patient participation by physicians. 3. Appreciation of patient's responsibility/rights to play an active role. 4. Awareness of choice. 5. Time: lack of time spent with pts was the barrier of pt. participation.

A total of 218 situations were observed. In most of the situations one or both parents, children and professionals were present during decision making process. Most decisions were of a medical nature, others were about nursing care. The children and their parents were usually involved in the decision-making process, but made few decisions themselves, e.g., children made the decision alone in 3 situations, and parents made the decision alone in

“actual” practice. No information about trustworthiness of data and finding

![Table of data](image-url)
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Purpose</th>
<th>Sample Characteristics</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Henderson and Shum (2003)</td>
<td>Hong Kong</td>
<td>To explore the extent to which Hong Kong Chinese population desires to participate in treatment DM about surgical intervention.</td>
<td>A convenience sample of 96 participants (49 surgical and medical patients and 47 nursing students). Among patients, 24 male and age 60.79±13.06, 25 female and age 52.36±14.75. Among students, 9 male and age 21.22±5.56, 38 female and age 20.34±0.88.</td>
<td>Cross-sectional qualitative study</td>
<td>Participants were given 3 scenarios: cardiac failure needing major surgery; cholecystitis needing routine surgery; and skin lesion needing minor surgery. Validity was supported by correlating ratings using backwards elimination. When the medical condition is not severe, collectively the student and patient group desired greater participation in the DM process. Younger patients desired greater collaboration with doctor in DM. Older patient sample desired greater participation by the doctor in DM than student group.</td>
</tr>
<tr>
<td>Kelly-Powell (1997)</td>
<td>US</td>
<td>To explore perceptions or experiences of patients who make health care decisions about treatment options under potentially life-threatening conditions, e.g. heart disease, cancer, and renal failure.</td>
<td>A purposive sample of 18 respondents, aged 26-81, mean age 60, with heart disease, renal failure, or cancer, from a teaching hospital, an outpatient kidney dialysis center, and a family practice in rural area (9 men and 9 women, 15 Caucasian, 2 African-American, and 1 native American).</td>
<td>Cross-sectional qualitative study using grounded theory method. Reflexive journal, prolonged interviews, repeated contacts, peer debriefing, purposive sampling, and member checking.</td>
<td>Reflexive reflexivity. Relationships with family and friends, or permitted them to maintain hope. Respondents’ decisions to accept treatment were personalized to correspond with their views of themselves within the context of their overall life stories or experiences. Using three specific strategies including interpreting the past, sustaining the current self, and anticipating the future, the patients chose to accept treatment which was consistent with their perceptions of previous experiences of themselves and significant others, allowed them to sustain their current normal lives and personal relationships with family and friends, or permitted them to maintain hope for the future. Findings reflect primarily the experiences of individuals who chose to treat their illnesses.</td>
</tr>
<tr>
<td>Larsson et al. (2007)</td>
<td>Sweden</td>
<td>To explore the meaning of patient participation in nursing care from a patient point of view.</td>
<td>A purposive sample of 26 Swedish informants from somatic inpatient care setting. (18 men and 6 women, age range 32–87, from gynaecological, rehabilitation, heart failure, and neurological ward and home)</td>
<td>Cross-sectional qualitative study using grounded theory method. Focus group interviews and constant comparative analysis.</td>
<td>Member checking. Two persons independently coded data. Interviews carried out by the same interviewer to enhance data quality. The core category ‘insight through consideration’ focused on the necessity for pt. to have appropriate, relevant, credible and sufficient info. and opportunity to consider participation in nursing care. Obliging atmosphere: patients needed to experience recognition and equal status, have adequate time, experience flexibility and consensus. Emotional response: nurses needed to be thoughtful, show respect for pt’s wishes so that the trust is generated. Concordance: pts should be willing to get involved and need a dialogue with nurses, need to receive help and reach a mutual commitment and goal with nurses. Rights: patients had legal right to be involved in DM and needed to be well informed and to have the sense of being accountable for themselves. Nearly all respondents (96%) preferred to be offered choices and to beholding interviews during hospital stay hindered open and free discussion and influence credibility. 3 to 5 informants in focus group was small number. Limited setting was used. No information.</td>
</tr>
</tbody>
</table>
al. (2005) the US
preferences for participation in DM, and how socio-demographic variables and health status influence people’s preferences.

Lown et al. (2009) the US
To explore how patients and physicians working together describe attitudes and behaviours that facilitate shared medical DM.

Mansell et al. (2000) the US
To determine whether type of illness and nature of decision predict patient’s preferences for involvement in making decisions.

O’Connor et al. (2003) Canada
To describe DM needs of Canadians when faced with ‘complex’ health decisions characterized by balancing advantages against disadvantages.
<table>
<thead>
<tr>
<th>Study Authors</th>
<th>Study Objective</th>
<th>Participants</th>
<th>Methodology</th>
<th>Data Analysis</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rosén et al. (2001)</td>
<td>To identify patients’ individual preferences for choice and shared DM.</td>
<td>1543 primary care patients. (47% age 60 or older; 581 male, mean age 58.4, 973 female, mean age 52.7)</td>
<td>Cross-sectional quantitative study</td>
<td>Self-administered questionnaire survey and statistical analysis</td>
<td>No information about validity and reliability testing. No know whether use random sample.</td>
</tr>
<tr>
<td>Sahlsten et al. (2009)</td>
<td>To explore RNs’ strategies to stimulate and optimise patient participation in nursing care.</td>
<td>A purposive sample of 16 experienced RNs in inpatient somatic care. (all female, from rehabilitation, gynaecological, orthopaedic, eye and medical wards)</td>
<td>Cross-sectional qualitative study</td>
<td>Focus group interview and content analysis</td>
<td>Small number of informants in focus groups. The setting was limited to inpatient somatic care.</td>
</tr>
<tr>
<td>Smith et al. (2009)</td>
<td>To explore understandings and experiences of involvement in DM among patients varying in education and functional health literacy.</td>
<td>A random sample of 41 men and 32 women from a community sample with lower education and an educated sample of university alumni. (aged between 55 and 64)</td>
<td>Cross-sectional qualitative study using phenomenology</td>
<td>Semi-structured interview and thematic analysis. Functional health literacy measures were used.</td>
<td>No knowing the influence of gender, ethnicity, and the experience of people with basic literacy skills. No information about trustworthiness and validity and reliability testing.</td>
</tr>
<tr>
<td>Zhang et al., China (2010)</td>
<td>To explore patients’ perceptions of participation in shared DM.</td>
<td>A random sample of 565 patients of an acute care hospital (387 patients aged under 40; most of patients are from medical and surgical setting; 274 male and 291 female).</td>
<td>Cross-sectional quantitative study</td>
<td>Self-administered questionnaire survey and statistical analysis</td>
<td>Not reported.</td>
</tr>
</tbody>
</table>
### Appendix 4 Characteristics of Studies on Health Care Decision-Making with Older People and Their Families (n=15)

<table>
<thead>
<tr>
<th>First author, year of publication, country</th>
<th>Aims(s)</th>
<th>Sample (age, gender, ethnicity) and setting</th>
<th>Design</th>
<th>Data collection and analysis</th>
<th>Rigour</th>
<th>Results</th>
<th>Summary of major limitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belcher et al. (2006) the US</td>
<td>To explore the views or the perceptions of older adults regarding patient participation/involvement in medication decision making (DM).</td>
<td>51 older people recruited from 3 senior centres and 4 physicians’ offices (19 men and 32 women; mean age 77, age range 65-89; 40 Caucasian, 10 African American, 1 Native American).</td>
<td>Cross-sectional qualitative study</td>
<td>Semi-structured interview and constant comparative analysis</td>
<td>Not reported</td>
<td>Different perceptions concerning the role of patient in medication DM: pts. don’t want to participate, pts. cannot be a part of DM, pts. can and should participate. Perceived lack of knowledge, low self-efficacy, fear and anxiety regarding illness, wanting doctor to tell them what to do, considering disease overwhelming, feeling powerless were pts’ factors. Trust in the physician was both a barrier and facilitator. Physician factors included doctors’ negative attitudes and behaviours and communication skills.</td>
<td>Participants from limited setting, not knowing perceptions of non-participants. Strategies for ensuring trustworthiness of data were not known.</td>
</tr>
<tr>
<td>Bogardus et al. (2001) the US</td>
<td>To describe types of family caregiver and physician treatment goals for frail elderly patients, and to ascertain the level of agreement between both parties on principal treatment goals.</td>
<td>Family caregivers and physicians for 200 consecutive older patients who were frail, cognitively impaired, living in community, and evaluated at an outpatient geriatric assessment centre (142 female and 58 male; mean age 78.7±8.3; 185 white).</td>
<td>Cross-sectional survey</td>
<td>Telephone interview with caregivers, self-administered questionnaire finished by physicians, and statistical analysis.</td>
<td>Not reported</td>
<td>Goals commonly chosen as most important by family caregivers and physicians pertained to day-to-day functioning, behavior and emotional health, safety, and medical issues. Although a substantial proportion of family caregiver and physician pairs shared at least one goal, agreement between caregivers and physicians on each of the broad goal categories was poor, and agreement on the most important goal was also poor.</td>
<td>Goals were measured only once. The study was performed at a single setting. The physicians were trained geriatricians who might know the goals of most concern to caregivers. Not knowing validity and reliability testing.</td>
</tr>
<tr>
<td>Chang et al. (2008) Korea</td>
<td>To describe the extent to which older Korean people want information about their health status and treatment and their desire to participate in health care DM.</td>
<td>A convenience sample of 165 older people from 5 apartment housing centers for older people, and 5 senior citizen centers (mean age 73.5, age range 65-96, 96 female and 69 male).</td>
<td>Cross-sectional quantitative study</td>
<td>Individual interview with participants using questionnaire, and statistical analysis,</td>
<td>Not reported</td>
<td>Participants’ desire to participate in DM when families were involved was higher, their desire to participate alone with physician was lower. The desire to seek information was higher for men, for those with higher education level, living with spouse or with spouse &amp; children compared with living with children only, for those earning more than USD 410/month, those who considered themselves ‘rather healthy’ compared with ‘rather unhealthy’. The desire to participate with physician was higher for those with higher education level, with no disease compared with 3 or more diseases. The desire to participate with families were higher for those in 60s, men, and those living alone, with spouse, or with children and spouse than for those living just with children.</td>
<td>Small convenience sample influenced generalizability. Participants’ desire to participate in DM for hypothetical diseases may differ from the actual desire. No information about validity and reliability testing.</td>
</tr>
<tr>
<td>Davies and Nolan (2003) the UK</td>
<td>To explore the experiences of decisions about nursing home entry or placements from the viewpoint of</td>
<td>A convenience sample of 37 people who had assisted a close relative to move into a nursing home (24 female and 13 male).</td>
<td>Cross-sectional qualitative study using constructivist approach</td>
<td>Semi-structured interview and analysis using constructivist method</td>
<td>Member checking</td>
<td>The 1st phase of transition was ‘making the best of it’, in which the relatives had an overwhelming desire to ensure that older people received the best possible care, and had 2 main concerns: wanting to make the right decision about the need for long-term care and wanting to choose the best available care home. The extent to which they were able to achieve these aims was</td>
<td>Convenience sample</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Country</td>
<td>Methodology</td>
<td>Sample Description</td>
<td>Data Analysis</td>
<td>Findings</td>
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<tr>
<td>Hasselkus et al.</td>
<td>1992</td>
<td>the US</td>
<td>Cross-sectional qualitative study</td>
<td>40 clinical visits involving 27 older patients, 31 family caregivers, and 11 physicians in the general</td>
<td>Clinical visits were audio-taped and qualitatively analyzed</td>
<td>The caregivers served as the primary resource to physician for historical information. They seemed to view themselves as practitioners and physician colleagues, and assumed traditional physician roles during visit, e.g., recommending treatment. They also demonstrated strong responsibilities regarding medication management. Physicians tended to view caregivers as substitutes for patients or second patients. Patient’s level of engagement seemed to be less than that of the others. In addition to health care, problem situations most often discussed were eating, moving around and risk. Participants brought little of social context of illness and care into the medical visit. Nurses believed that patient’s role influenced participation, the more active the patient the greater their participation. Other factors included: patients’ physical/psychological ability to participate and make rational decisions, conflict between patient and family/carer needs, patients’ willingness to participate, over protection of pts by nurses, and allowing pts’ time to participate. 3 major processes in the decision of institutionalization included: breaking harmony (recognizing duties, recognizing imbalance and recognizing burdens), rebuilding harmony (setting priorities, setting boundaries and coping efforts) and evolution (transition from intention to action of institutionalization). 4 influencing factors were quality of the relationship between older people and family, characteristics of older people, financial condition of family, and perceived public opinion toward institutionalization.</td>
<td>Small sample size, not knowing non-participants’ interactions in medical setting. No information about trustworthiness of data and finding.</td>
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<tr>
<td>Jewell et al.</td>
<td>1996</td>
<td>the UK</td>
<td>Cross-sectional qualitative study</td>
<td>A convenience sample of 9 primary nurses from 2 elderly care units specializing in rehabilitation.</td>
<td>Focus group interview and content analysis</td>
<td>Convenience sample, no information about trustworthiness of data and finding.</td>
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<td>Kao and Stuitbergen</td>
<td>1999</td>
<td>Taiwan</td>
<td>Cross-sectional qualitative study</td>
<td>9 family members whose older people resided in 2 nursing homes (family members: 3 male and 6 female, mean age 47.67; patients: mean age 73.33, age range 67-90).</td>
<td>Semi-structured interview and content analysis</td>
<td>Small sample size and homogeneity of non-random sample influenced generalisability. Participants might be more active and willing to talk than general population of carers. Limited sample size influenced generalisability. Strategies for ensuring trustworthiness of data were not known.</td>
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<tr>
<td>Lundh et al.</td>
<td>2000</td>
<td>Sweden</td>
<td>Cross-sectional qualitative study</td>
<td>A purposive sample of 14 spouses who had placed a partner in a care home for older people (11 female and 3 male, age range 68-90).</td>
<td>Semi-structured interview and constant comparative analysis</td>
<td>The placement process had 4 temporal dimensions: making the decision, making the move, adjusting to the move, reorientation. Placement decision was a growing awareness of their inability to carry on a caring role. The possibility of caring arrangements was raised by home helps, nurses or children. The professionals’ making final decisions reflected ‘expert’ driven nature. The move was relating to feelings of powerlessness, separation, and self</td>
<td>Limited sample size influenced generalisability. Strategies for ensuring trustworthiness of data were not known.</td>
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<tr>
<td>Study</td>
<td>Design/Methodology</td>
<td>Sample Description</td>
<td>Findings</td>
<td>Notes</td>
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<td>Menne and Whitlatch (2007)</td>
<td>Cross-sectional quantitative study</td>
<td>215 individual with dementia (IWD)-family carer dyads recruited through family caregiver alliance, community service division of an institute, and aging center (IWD mean age 76, even number of male and female, 31% African American).</td>
<td>The decision to seek care was not usually a deliberate choice made by older person. Although carers were involved actively in both countries, older person was more likely to play active role in UK. Professionals played a major part in DM. Doctors exerted a major influence in both countries, being involved in and recommending admission. Social workers were far more likely to both be involved in and recommend admission in the UK. Nurses were far less likely to be involved in discussions, but figured more prominently in the UK than US, both in hospital and community. Carer or older person was more likely to make final decision. Professionals played a major part in DM. Doctors exerted a major influence in both countries, being involved in and recommending admission. Social workers were far more likely to both be involved in and recommend admission in the UK. Nurses were far less likely to be involved in discussions, but figured more prominently in the UK than US, both in hospital and community. Carer or older person was more likely to make final decision.</td>
<td>No validity &amp; reliability testing. Cross-sectional design limited ability to make true causal attributions. Secondary analysis. IWDs were not queried about level of diagnosis awareness, which plays a key role in DM involvement.</td>
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<tr>
<td>Nolan and Dellasega (2000)</td>
<td>Cross-sectional mixed quantitative study</td>
<td>48 carers in the UK and 54 carers in the US who had placed a relative in a nursing home (mean age of older person: US 80 UK 82; mean age of carer: US 60 UK 61; gender of older person: US female 27 male 27, UK female 37 male 11; gender of carer: US female 43 male 11, UK female 38 male 10).</td>
<td>The decision to seek care was not usually a deliberate choice made by older person. Although carers were involved actively in both countries, older person was more likely to play active role in UK. Professionals played a major part in DM. Doctors exerted a major influence in both countries, being involved in and recommending admission. Social workers were far more likely to both be involved in and recommend admission in the UK. Nurses were far less likely to be involved in discussions, but figured more prominently in the UK than US, both in hospital and community. Carer or older person was more likely to make final decision. Professionals played a major part in DM. Doctors exerted a major influence in both countries, being involved in and recommending admission. Social workers were far more likely to both be involved in and recommend admission in the UK. Nurses were far less likely to be involved in discussions, but figured more prominently in the UK than US, both in hospital and community. Carer or older person was more likely to make final decision.</td>
<td>Non-random sample influenced generalisability. No information about validity and reliability testing, and trustworthiness of data and finding.</td>
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<tr>
<td>Ross et al. (2001)</td>
<td>Cross-sectional descriptive study, and primarily using qualitative method.</td>
<td>A stratified sample of 50 older people with musculoskeletal pain from different settings; physicians’ practice, community health centre, and seniors’ centre (of 47 respondents, 15% aged between 60 and 65; 33% between 66 and 70; 33% between 71 and 75; and 10% over 75).</td>
<td>Individuals who reported more decision-making involvement were younger, female, had more education, had a non-spousal caregiver, had fewer months since their diagnosis, exhibited fewer problems with activities of daily living and fewer depressive symptoms (based on caregiver report), and placed more importance on autonomy/self-identity.</td>
<td>Convenience sample influenced generalisability.</td>
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<tr>
<td>Rotar-Pavlič et al. (2008)</td>
<td>Cross-sectional qualitative</td>
<td>A stratified sample of 39 older patients at home or health centres, and 26</td>
<td>The patients saw involvement as a mutual activity where an improved relationship between GP and patient led to better treatment outcomes. Trust in GP is essential. Involvement also influenced expectations about aging and pain influenced DM. Content of decisions included whether to intervene and what strategy to take. Types of decisions included to ignore their pain and to use distraction. Self-care strategies to manage pain included exercise, application of heat and cold, and medications. Decisional conflict was minimal, and respondents didn’t find decisions difficult to make. Consultation with family and friends superseded that with professionals. Material resources were also used to assist in DM.</td>
<td>No other strategies to ensure trustworthiness were reported.</td>
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<td>Study</td>
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<td>Participants</td>
<td>Methodology</td>
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<tr>
<td>Rydman and Tornkvist (2009) Sweden</td>
<td>To examine how older persons in need of home-nursing care and their relatives experience the discharge process and develop a model that explains the experience.</td>
<td>14 older patients and 12 family members in different settings: geriatric, orthopaedic, infectious disease, neurological and rheumatological unit (older patients mean age 79, 7 male and 7 female).</td>
<td>Cross-sectional grounded theory study</td>
<td>Semi-structured interview and constant comparative analysis</td>
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<td>Tutton (2005) the UK</td>
<td>To explore the meaning of participation for older people in hospital and their health care workers, and ways in which staff can enhance patient participation in their care.</td>
<td>18 older patients and 29 staff in a ward which took patients with high levels of nursing need, requiring slow-stream rehabilitation or having complex discharge requirements.</td>
<td>Action research</td>
<td>Focus group and in-depth interview, and qualitative data analysis. The action undertaken with staff aimed at raising their awareness of participation. Small changes, e.g. use of patient biographical booklet were introduced.</td>
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<td>Walker and Dewar (2001) the UK</td>
<td>To investigate the extent to which carers were involved in decisions relating to care planning.</td>
<td>20 carers of older people with dementia, 17 qualified and assisting nursing staff, 5 doctors, 2 occupational therapists, 2 social workers, 3 community psychiatric nurses in a respite and assessment ward within a psychiatric unit.</td>
<td>Cross-sectional qualitative case study</td>
<td>Individual or focus group interview, non-participant observation, documentation, and constant comparative analysis.</td>
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shared DM in health care by elderly patients and their GPs in family medicine in Slovenia. study were analyzed, demonstrated good congruity. International consistency of coding evaluated. Writing memo. Member checking. Trying to entering research with few pre-conceptions. included respect for their particular preference and circumstances. The GPs considered involvement to be a process based on consent, where GP advised pt on diagnosis and treatment options. Some patients and GPs felt that patient involvement was not possible. Some patients evaluated involvement according to how well their expectations were met. But GPs saw patient’s expressing expectations as a danger which might ‘disturb’ treatment plan, and impede health care. 3 skills of professionals facilitated satisfaction of needs in preparation: (i) caring competence involving giving quality medical and nursing care; (ii) individualized commitment concerning adjustments to meet the need for information and other arrangements; (iii) planning for life at home including planning and taking care of forthcoming needs. When older people and/or relatives distrusted info, received and decisions made by profs, they checked information with others, or searched for information in books. When disagreeing with profs, they questioned decisions and argued for their point of view. Four themes were related to pt. participation: facilitation, partnership, understanding the person, and emotional work. Facilitation including: enabling pt. to lead the interaction, and providing choices. Partnership involved: respecting for the person; trusting between pts. and staff; negotiating care; and facilitating pts.’ control over their own activities. Understanding pts.’ personal history, making connections with pts., knowing a person, understanding illness and dependency, and viewing participation as a dynamic process that changed over time, can facilitated pt. participation. Gaining and retaining an emotional connection between individuals, accepting the other, and managing emotions in a positive way, can facilitate pt. participation. Carers reported four markers of satisfactory involvement: feeling that information is shared; feeling included in DM; feeling that there is someone you can contact when you need to; and feeling that the service is responsive to your needs. The majority of carers felt dissatisfied with level of involvement. Two main sources of difficulty were found: hospital systems and the relationship between nursing staff and carers. The meeting usually was dominated by agenda of staff, often leaving carers feeling disempowered and undervalued, feeling disappointed, feeling that decisions had been made without them. Researchers might have preconceptions. Voluntary participation might yield a sample with strong views about discharge. Limited setting influenced the generalisability. It’s difficult to access frail patients’ views of how they take part in their care through interview. Small numbers of staff provided limited views in focus groups. Limited strategies for ensuring trustworthiness of data.
validation for data interpretation.

Carers thought it was the consultant who made decisions. Both staff and carers said that contact largely relied on carers' initiative. Staff were not proactive in seeking information from carers, and carers were often reluctant to disturb staff.
### Appendix 5 Characteristics of Qualitative Studies on Decision-Making with Stroke Patients and Families (n=19)

<table>
<thead>
<tr>
<th>Author, year of publication, country</th>
<th>Aim(s)</th>
<th>Sample (age, gender, ethnicity) and setting</th>
<th>Design</th>
<th>Data collection and analysis</th>
<th>Rigour</th>
<th>Results</th>
<th>Summary of major limitation</th>
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<tbody>
<tr>
<td>Alaszewski et al. (2008) The UK</td>
<td>To understand health professionals’ information provision about stroke.</td>
<td>23 health professionals from acute care, community care, and primary care settings; 19 stroke patients aged between 45 and 86 years old; 6 relatives aged 49-75 in the UK. (patients 9 male 10 female; relatives 2 male 4 female)</td>
<td>Cross-sectional</td>
<td>Individual interview and focus group and qualitative analysis</td>
<td>No information about strategies to ensure validity and reliability.</td>
<td>Good and accurate information enabled patients and carers to make informed treatment decisions; it easier to comply with or accept medication when they were actively involved in decision making or established trust in professionals; sometimes patients did not get professional support when wanting to make decisions; some carers reported involvement in all decision making activities.</td>
<td>Small sample size, no strategies taken to ensure validity and reliability.</td>
</tr>
<tr>
<td>Andersson and Hansebo (2009) Sweden</td>
<td>To explore older stroke patients’ experiences about nursing care from a gender perspective.</td>
<td>A convenience sample of 5 male and 5 female older patients aged between 66 and 75 years from a stroke rehabilitation ward in Sweden.</td>
<td>Cross-sectional</td>
<td>Open-ended interview and content analysis</td>
<td>Fewer strategies to ensure trustworthiness: giving sufficient information about data analysis procedures, having discussion and comparison during data analysis.</td>
<td></td>
<td>Convenience sample and only one ward used to recruit participants influenced transferability.</td>
</tr>
<tr>
<td>Brereton and Nolan (2002) The UK</td>
<td>To explore the perceptions of health care providers regarding who is responsible for selected role functions in decision making.</td>
<td>A purposive sample of 14 new British family carers of stroke survivors in three different settings: a general acute medical admission ward, a specialist stroke unit, and a community. (6 male, 8 female; aged 32-93)</td>
<td>Longitudinal prospective study</td>
<td>Semi-structured interview and constant comparative analysis</td>
<td>Member checking</td>
<td>Carers were required to make decisions about future care of patients without adequate understanding about stroke; had sense of uncertainty and lack of confidence; sought information or partnership with other relatives; and wanted more involvement in hospital care.</td>
<td>Limited strategies used to ensure validity and reliability.</td>
</tr>
<tr>
<td>Brereton and Nolan (2003) the UK</td>
<td>To understand the experiences of new carers of stroke survivors.</td>
<td>A purposive sample of 18 new British family carers (8 male, 10 female; aged 32-93).</td>
<td>Longitudinal prospective study</td>
<td>Semi-structured interview and constant comparative analysis</td>
<td>Member checking</td>
<td>Carers had sense of bewilderment, took initiatives and sought partnership and help and support from both families and professionals, and sought and collected information and tried to learn caring skills and be involved in patient care.</td>
<td>Limited strategies used to ensure validity and reliability.</td>
</tr>
<tr>
<td>Gibson (2002) the UK</td>
<td>To explore decision making in carotid endarterectomy from patient’s and surgeon’s perspectives.</td>
<td>A convenience sample of 6 British patients aged between 50 and 79 years old and 1 surgeon in vascular surgery outpatient clinic (3 male, 3 female).</td>
<td>Cross-sectional, Grounded theory study</td>
<td>Semi-structured interview and constant comparative analysis</td>
<td>No information about strategies to ensure validity and reliability.</td>
<td>Patients regarded decision about carotid endarterectomy as theirs, not surgeon’s; surgeons’ role was advising treatment options, but their role was making treatment decisions; both patients and surgeon used intuition in decision making.</td>
<td>Small and convenience sample size, no strategies taken to ensure validity and reliability.</td>
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<tr>
<td>Hedberg et al. (2002)</td>
<td>To investigate how</td>
<td>14 care-planning meetings were</td>
<td>Cross-sectional</td>
<td>Audio-recorded</td>
<td>Inter-rater</td>
<td>3 types of communication during decision making included</td>
<td>Limited sample</td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Participants</td>
<td>Methods</td>
<td>Findings</td>
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<td>al. (2008)</td>
<td>Sweden</td>
<td>stroke survivors, relatives, and professionals</td>
<td>held in 1 geriatric rehabilitation ward at a hospital, and at 3 rehabilitation centres.</td>
<td>sectional mixed qualitative and quantitative study care-planning meetings were transcribed, and together with observational notes, were analyzed using qualitative and quantitative methods. Reliability was calculated and disagreement was resolved through discussion. Advising, summarising, and intervening. Patients, relatives, and nurses mainly used advising; social workers mainly used summarising; and nurses also used intervening. 2 communicative approaches included ‘open-minded’ and ‘aim-driven’ approaches. The total amount of words used by social workers, nurses and occupational therapists were more than those used by patients and relatives.</td>
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<td>Hjelmblink (2008)</td>
<td>Sweden</td>
<td>To explore meaning of life after stroke from patients’ points of view.</td>
<td>19 older Swedish stroke patients aged between 56 and 89 during the first year post stroke (8 male, 11 female).</td>
<td>Cross-sectional study, interview and qualitative data analysis. Validity was ensured by avoiding pre-conceptions, and discussion between co-researchers. Some survivors demonstrated strong needs for autonomy and regarded it as the most important, did not want to involve families in decision making, and expected families to agree with or support their decisions.</td>
<td>Limited sample size and strategies of ensuring validity and reliability.</td>
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<td>Huby et al. (2007)</td>
<td>the UK</td>
<td>To investigate how older patients and professionals understand decision making about discharge planning after acute hospitalization, and how practice influences their decision making.</td>
<td>A purposive sample of 22 patients aged 60+ (8 stroke patients aged between 60 and 81, 4 male and 4 female) and 11 professionals (2 ward nurses, 3 medical consultants, 2 community nurses, 1 physiotherapist, 1 occupational therapist, 1 hospital social worker, and 1 discharge coordinator) from a stroke unit, a geriatric assessment and rehabilitation unit, and a general medical ward in a hospital in the UK.</td>
<td>Cross-sectional, ethnography study. Data from semi-structured interview and observation were analyzed using ethnography principles. No information about validity and reliability testing reported. Patients trusted in and did not interfere with professionals’ decisions. Staff found it difficult to involve patients in decision making, but wanted to provide information. Patients felt that they were unable to make decisions due to declined health condition after stroke, and increasingly relied on families to make decisions for them.</td>
<td>Lack of strategies to testing validity and reliability.</td>
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<tr>
<td>Mangset et al. (2008)</td>
<td>Norway</td>
<td>To explore factors influencing stroke patients’ satisfaction with rehabilitation following stroke.</td>
<td>A purposive sample of 12 older stroke patients aged between 60 and 87 years in a stroke rehabilitation unit in Norway (5 male, 7 female).</td>
<td>Longitudinal prospective study. Semi-structured interview and data analysis based on phenomenological method. No information about validity and reliability testing reported. Patients had different attitudes towards participation in medical decision making, some patients wanted their autonomy to be respected, some felt frustrated when being required to make decisions, some trusted in professionals and wanted doctors to make decisions.</td>
<td>Limited sample size, limited setting influenced transferability.</td>
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<td>Marques et al. (2006)</td>
<td>Brazil</td>
<td>To investigate changes of family relations occurred after patients suffered</td>
<td>34 participants in 11 families of older stroke patients aged from 62 to 84 years in an emergency unit in Brazil (7 male patients, 4 female</td>
<td>Cross-sectional study, interview and qualitative data analysis. No information about validity and reliability testing reported. There were positive changes in family relations relating to decision making, e.g., relatives provided support to make treatment decisions for patients, patients’ poor health reduced their decision making ability and increased their wives’ size influenced transferability.</td>
<td>Lack of strategies to testing validity and reliability.</td>
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<td>Study</td>
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<td>Methods</td>
<td>Data Collection Strategies</td>
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<td>Molczij et al. (2008)</td>
<td>Netherlands</td>
<td>To investigate decision making about help-seeking at the time of stroke.</td>
<td>20 stroke survivors aged between 46 and 58 years from hospital, community-based stroke support service, and primary health care service in New Zealand (12 male, 8 female). Both purposive and theoretical sampling were used.</td>
<td>Cross-sectional retrospective grounded theory study</td>
<td>Using independent researcher to analyze data, and using team meeting to discuss data analysis, in order to ensure rigour. No information about validity and reliability testing reported. Participants went through a process of recognition, interpretation and negotiation, which led to help-seeking or no action. Factors influencing help-seeking decision included: making sense of symptoms, maintaining sense of normality, presence and influence of another person, and perception of medical services, which facilitated or delayed help-seeking behaviour.</td>
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<td>Olofsson et al. (2005)</td>
<td>Sweden</td>
<td>To explore stroke patients’ and families’ decision making about a range of issues including help-seeking at the onset of stroke, health care during hospitalization and at discharge, and family care after discharge and returning home.</td>
<td>9 Swedish patients aged between 64 and 83 years and 5 families in their homes (patient: 4 male, 5 female).</td>
<td>Cross-sectional</td>
<td>No information about validity and reliability testing reported. Most of patients actively made decisions of seeking help at the time of stroke. During hospitalization, professionals made decisions for patients. When returning home after discharge, they tried to regain decision making on their lives and required family support. Patients and families emphasized the importance of professional support which provided encouragement, information, advice, confirmation or feedback.</td>
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<td>Payne et al. (2009)</td>
<td>the UK</td>
<td>To identify patients’ and families’ experiences of acute stroke and preferences for end-of-life care.</td>
<td>A purposive sample of 28 acute stroke patients with 59% aged over 65, who had either high or low disability, and 25 family members from two general hospitals in the UK (68% male patients).</td>
<td>Cross-sectional. Exploratory study</td>
<td>Trustworthiness was established by coding data by independent researchers and reaching agreement, and expert examining data analysis. Patients’ autonomy increased in comparison with those during rehabilitation. Patients wanted to be involved in medical decision making. Families participated in decision making regarding resuscitation, and felt difficult to make decisions about ‘inserting PEG tube’ or ‘Do Not Resuscitate’. No patients were referred to palliative care or given choice of early discharge to home. Families were given few opportunities for participation in decision making about place or style of end-of-life care. None of families were given the option of patient’s dying at home. Limited sample which excluded patients with aphasia or cognitive impairment, who were likely to die.</td>
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<td>Proot et al.’s (2000a)</td>
<td>Netherlands</td>
<td>To explore stroke patients’ needs and experiences of autonomy at discharge after rehabilitation.</td>
<td>20 stroke patients from rehabilitation wards of three nursing homes aged between 50 and 85 in Netherlands (12 male, 8 female; mean age 72).</td>
<td>Cross-sectional grounded theory study</td>
<td>Patients experienced increased decision making autonomy during rehabilitation due to facilitating factors from patient, families, health professionals, and nursing home environment (improved ability and self-confidence; attentiveness and support from professionals; frequently visiting). Lack of other strategies to ensure validity and reliability.</td>
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<td>Proot et al. (2000b)</td>
<td>Netherlands</td>
<td>To determine facilitating or constraining factors regarding patient autonomy during rehabilitation.</td>
<td>A consecutive sample of 17 stroke patients aged between 50 and 85 in rehabilitation wards in nursing homes in Netherlands (10 male, 7 female; mean age 73).</td>
<td>Cross-sectional grounded theory study</td>
<td>Patients experienced increased decision making autonomy during rehabilitation due to facilitating factors from patient, families, health professionals, and nursing home environment (improved ability and self-confidence; attentiveness and support from professionals; frequently visiting). Factors influencing help-seeking decision included: making sense of symptoms, maintaining sense of normality, presence and influence of another person, and perception of medical services, which facilitated or delayed help-seeking behaviour.</td>
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<td>Study</td>
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<td>Study Design</td>
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<td>Proot et al. (2002) Netherlands</td>
<td>To explore autonomy of stroke patients in rehabilitation wards from the perspectives of health professionals.</td>
<td>27 health care providers (6 nurses, 7 nursing aides, 3 doctors, 3 physiotherapists, 3 occupational therapists, 3 speech therapists, and 2 social workers) from 3 nursing homes in Netherlands (mean age 36, age range 25-54; 7 male, 20 female).</td>
<td>Longitudinal grounded theory study</td>
<td>Semi-structured interview and constant comparative analysis</td>
<td>Data and investigator triangulation, member checking, and peer debriefing to ensure validity.</td>
<td>Participants identified process of patients' regaining autonomy and influencing factors. The severity and comprehensiveness of disability post-stroke was an inhibiting factor. Taking responsibility was used by patients to make decisions. If family acted as a go-between rather than took over patients' decision making, and showed positive anticipation towards patients, patient autonomy was facilitated. Professionals' strategies promoting patient autonomy included giving information, assessing and training patient, making decisions for patient if needed, encouraging patient to make decisions, decreasing paternalism or enhancing patient decision making, cooperation with patients and families, risk taking, and team work. 'Institutionalisation of professionals' inhibited patient decision making. 2 approaches by professionals facilitated patient autonomy. One included full support for patient care on admission, moderate support and supervision during rehabilitation, and reduced supervision at discharge. The other consisted of changes from paternalism on admission, through partial paternalism regarding treatment decisions, to shared decision making at discharge. Patients experienced increased autonomy and reduced support and supervision over time, but reported prolonged and continuous paternalism on their decision making. Lack of information was an inhibiting factor. End-of-life decision making (on artificial hydration and nutrition, treatment of infections, and rehabilitation) for patients who survived longer than expected were complex. For example, families were less willing to commence feeding than professionals, since they wished not to prolong patients' suffering; however professionals might have similar concerns, or might feel the patient could be starving and hungry or make some recovery. So families might ask for advice or support from palliative care team when making and reviewing treatment decisions.</td>
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<tr>
<td>Proot et al. (2007) Netherlands</td>
<td>To understand about autonomy during the whole rehabilitation process from admission to discharge from stroke patients' perspectives.</td>
<td>A consecutive sample of 22 stroke patients aged between 50 and 85 undergoing rehabilitation in 3 nursing homes in Netherlands (patients participating all interviews: 12 male, 8 female; mean age 72).</td>
<td>Longitudinal grounded theory study</td>
<td>Interview and constant comparative analysis</td>
<td>Data and investigator triangulation, member checking, and peer debriefing to ensure validity.</td>
<td>Sample was limited to care providers.</td>
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</tr>
<tr>
<td>Rogers and Addington-Hall (2005) the UK</td>
<td>To explore nursing and medical care received by dying stroke patients at the end of their life.</td>
<td>Families and professionals of 22 British patients aged between 58 and 106 years who died in an acute stroke unit (11 male, 11 female).</td>
<td>Prospective study</td>
<td>Non-participant observation and interview and constant comparative analysis</td>
<td>No information about validity and reliability testing reported</td>
<td>Only using interview to collect data.</td>
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<tr>
<td>Slingsby (2006) Japan</td>
<td>To examine how health professionals in Japan provide rehabilitation therapy to stroke patients.</td>
<td>57 Japanese health professionals (nurses, doctors, clinical psychologists, physiotherapists, occupational therapists, and speech therapists), 48 stroke patients, and 57 Japanese health professionals (nurses, doctors, clinical psychologists, physiotherapists, occupational therapists, and speech therapists).</td>
<td>Cross-sectional</td>
<td>Non-structured and semi-structured interviews, and non-participant</td>
<td>Data triangulation, member checking</td>
<td>Lack of strategies to testing validity and reliability.</td>
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</table>

constraining patient autonomy were also discovered (multi-morbidity; lack of information from professionals; over-protect from family). |

Sample was limited to care providers.
26 families from a national hospital specialising in treatment of stroke and other neurological diseases (21 professionals undergoing interviews: mean age 42, age range 25-59; 9 male, 12 female).

observation, constant comparative analysis
decision over patient’s decision, and family relationship over patient’s autonomy. Both professionals and patients thought this was in patients’ interests, and preferred families to make decisions for or with patients.
## Appendix 6 Characteristics of Quantitative Studies on Decision-Making with Stroke Patients and Families (n=11)

<table>
<thead>
<tr>
<th>Author, year of publication, country</th>
<th>Aim(s)</th>
<th>Sample (age, gender, ethnicity) and setting</th>
<th>Design</th>
<th>Data collection and analysis</th>
<th>Rigour</th>
<th>Results</th>
<th>Summary of major limitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almborg et al. (2008) Sweden</td>
<td>To explore stroke patients’ perceptions of participation in discharge planning and factors related to their perceived participation.</td>
<td>A consecutive sample of 188 Swedish patients with acute stroke from a hospital (mean age 74; male 105, female 83).</td>
<td>Cross-sectional</td>
<td>Face-to-face interview using questionnaire</td>
<td>Instruments were validated.</td>
<td>72 to 90% of patients perceived they had participated in discharge planning by receiving and understanding information. 29 to 38% reported they had participated in treatment discussion. 15 to 47% felt they had participated in decision making about needs and goal setting. Moreover, patients’ age, education level and performance of ADL were found to be significantly related to perceived participation in discharge planning. 12% of patients reported they were not willing to undergo surgery. Patients with older age, black race, no previous surgery, lower level of locus of control, less trust of physician, and less social support were significantly more likely averse to surgery.</td>
<td>Exclusion of patient with aphasia or moderate to severe cognitive impairment might influence generalisability of findings.</td>
</tr>
<tr>
<td>Bosworth et al. (2004) the US</td>
<td>To examine factors influencing patients’ aversion of carotid endarterectomy.</td>
<td>A cohort of 1065 patients who were referred for carotid artery stenosis evaluation at medical centres (99% male; mean age 67.5; 80.6% white; 19.4% black; no socio-economic data reported).</td>
<td>Prospective cohort study</td>
<td>Secondary analysis of data: patients’ demographic, clinical, psychosocial information, and response to question assessing their aversion to carotid endarterectomy and related perceptions</td>
<td>Some instruments used were validated.</td>
<td>The median interval between symptom onset and help-seeking decision and emergency department arrival were 90 and 335 minutes respectively. The time between symptom onset and first call for medical help accounted for 45% of the prehospital delay, indicating prehospital delay was mainly due to decision delay. Patients’ older age and lower severity increasingly delayed help seeking decision.</td>
<td>Secondary analysis of data; the large majority of male sample.</td>
</tr>
<tr>
<td>Chang et al. (2004) Taiwan</td>
<td>To investigate the extent of and factors influencing prehospital delay after acute stroke and delay in help-seeking decisions.</td>
<td>196 Taiwanese patients with acute stroke presenting to emergency department of a hospital within 48 hours of symptom onset, and their families or witnesses (Mean age 65, 94 aged 18-64, 89 aged 65-80, 13 aged 81-87; male 116, female 80).</td>
<td>Prospective observational study</td>
<td>Data regarding demographic information and circumstances between onset of stroke and arrival at emergency department were collected using interview and analyzed statistically</td>
<td>No information about validity and reliability testing.</td>
<td>The median interval between symptom onset and help-seeking decision and emergency department arrival were 90 and 335 minutes respectively. The time between symptom onset and first call for medical help accounted for 45% of the prehospital delay, indicating prehospital delay was mainly due to decision delay. Patients’ older age and lower severity increasingly delayed help seeking decision.</td>
<td>Lack of information about validity and reliability testing.</td>
</tr>
<tr>
<td>Christensen and Anderson (1989) the US</td>
<td>To explore spouses’ adjustment to stroke with or without aphasia.</td>
<td>11 spouses of nonaphasic stroke patients and 11 spouses of aphasic stroke patients at 1 to 1.5 years after stroke in the US (nonaphasic patient spouses’ mean age 61.4, female 7 male 3; aphasic patient spouses’ mean age 62.8, female 9 male 1).</td>
<td>Cross-sectional</td>
<td>Self-administered questionnaire survey about demographic information, daily living activities (role change, emotional problems and social adjustment) of spouses, and communication deficits of patients</td>
<td>No information about validity and reliability testing of study instrument.</td>
<td>77% of aphasic patients’ spouses reported that they ‘almost always’ experienced role changes including making medical and financial decisions, taking dominant role in family, and giving personal care to patients. However, only 38.4% of nonaphasic patients’ spouses reported this role change. Spouses of aphasic patients reported the greater role changes as their major adjustments to stroke.</td>
<td>Non-representative sample and lack of validity and reliability testing, influenced generalisability of findings.</td>
</tr>
<tr>
<td>Health Care Commission (2005) the UK</td>
<td>To explore stroke patients’ experiences of being in hospital and the care received following</td>
<td>1713 patients from 51 acute hospital trusts (male 940, female 742; 7% aged 16-50, 12% aged 51-60, 23% aged</td>
<td>Cross-sectional</td>
<td>National questionnaire survey</td>
<td>Questionnaire was pilot tested, refined, and</td>
<td>Many participants would like to be more involved in decision making about care. 52% of patients reported they hadn’t participated as much as they desired in treatment and care decisions during hospitalisation, of whom 19% 26% completed survey with help from other people, 16% completed by</td>
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</tbody>
</table>
Health Care Commission (2006) the UK
To explore stroke patients’ perspectives about experiences of care and support received approximately one year after discharge from hospital.
875 patients with stroke from 51 acute hospital trusts (male 519, female 356; 7% aged 16-50, 12% age 51-60, 26% aged 61-70, 32% aged 71-80, 23% aged 81 and over; 93.44% white British; 187 had lower socio-economic status, 227 had higher socio-economic status, 461 in between). Cross-sectional National follow-up questionnaire survey No information about validity and reliability testing. Many patients reported they preferred more involvement in care and treatment decision making; 59% felt they hadn’t been involved as much as they wanted, and within whom 15% reported they had not been involved at all. Of the participants who wanted to be involved in decision about the best medicine, 20% said they hadn’t been involved as much as they wanted, and 35% said they had only been involved to some extent. Of the participants who reported they had received enough information about stroke, 70% said they had definitely been involved enough in care and treatment decisions. However, of those who reported not receiving enough information, only 17% felt they had been involved as much as they preferred in decision making.

Kapral et al. (2006) Canada
To explore gender differences in patient decision making about stroke care.
A consecutive sample of 586 Canadian patients (45% women, 21% stroke or TIA history) was recruited from stroke, vascular, and general internal medicine clinics at two acute care hospitals. (women mean age 55, men mean age 62) Cross-sectional Self-ministered questionnaire survey using simulated patient scenarios No information about validity and reliability testing. Women were less likely than men to accept thrombolysis, but both of them were equally likely to accept carotid endarterectomy. Women were less confident than men in decisions, were more likely to indicate fear of risks of treatment, fear of being a burden to others, and need for more information as important reasons used in decisions. Women were less likely to identify confidence in medical professionals as important. Women were less likely to enjoy taking risks in stroke care decision making, but more likely to indicate security as important, and preferred shared or independent decision making rather than having decisions made by doctors.

Rosenbaum et al. (2004) the US
To investigate informed consent in tissue plasminogen activator (tPA) treatment.
A retrospective cohort of 63 American patients who were given tPA for acute ischemic stroke in 10 hospitals. (male 29, female 34, mean age 71, age range 39-92) Retrospective cohort study Patients’ medical records were reviewed and secondary analysis was conducted. No information about validity and reliability testing. Among 63 patients receiving tPA, 53 (84%) had informed consent, and 16 out of 53 (30%) gave their own consent. Among patients with adequate decision making ability, 5 out of 8 (63%) had their consent made by surrogate. However, among patients with inadequate ability, 7 out of 38 (18%) gave their own consent. A majority of participants (93%) wished to receive detailed and precise information on risks and benefits of others, lower response rate from women, black and minority, living in deprived areas, aged 80+ or 50-. These influenced the responses.

Slot and Berge (2009)
To explore patients’ preferred content and discharge.
61-70, 33% aged 71-80, 25% aged 81 and over; 94% British; respondents living in less socio-economically deprived areas). Cross-sectional Questions about content and type of treatment No detailed information reported they were not involved in decision making at all. Secondary analysis; relying on data from chart to explore informed consent. Lack of detailed information about
<table>
<thead>
<tr>
<th>Country</th>
<th>Setting Description</th>
<th>Participants</th>
<th>Study Design</th>
<th>Data Collection Methodology</th>
<th>Findings</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Norway</td>
<td>Format of information on treatment effect, and preferred level of involvement in decision making.</td>
<td>Matched control participants who were at risk of stroke from 5 day care centres. (patient: 37 male, 38 female, mean age 78; control: 37 male, 38 female, mean age 73)</td>
<td>Cross-sectional</td>
<td>Semi-structured interview and statistical analysis</td>
<td>3 scales were used to collect data. thrombolysis. 96 participants (64%) wanted oral information, while 54 (36%) preferred both oral and written information before decision making. Most participants (91%) preferred shared treatment decision-making. 13 participants (9%) didn’t want to participate in decision making and wanted doctor to make final decision only.</td>
<td>Validity and reliability.</td>
</tr>
<tr>
<td>Wellwood et al. (1994) the UK</td>
<td>To understand patients’ and carers’ perceptions and knowledge of stroke.</td>
<td>A consecutive sample of 65 British patients with acute stroke admitted to a hospital and 80 carers. (patients: 35 male, mean age 69)</td>
<td>Cross-sectional</td>
<td>Not testing validity and reliability of the study instrument</td>
<td>42 patients (65%) and 73 carers (91%) reported they wanted to know all detailed information about stroke and treatment, while 5 patients (8%) preferred not to know and depend on professionals' decisions. 20 patients (31%) and 40 carers (50%) preferred to discuss treatment decisions with professionals during hospital stay. 35 patients (54%) and 30 carers (38%) wanted professionals to make decisions.</td>
<td>Validity and reliability testing were not carried out. Missing data or incomplete responses. Generalisability of finding was influenced.</td>
</tr>
<tr>
<td>Zhang et al. (2004) China</td>
<td>To explore the effect of a home-based rehabilitation nursing intervention for stroke patients’ family carers on their caring ability.</td>
<td>60 Chinese family carers of stroke patients in community setting were randomly assigned to either an intervention or control group. (intervention group: female, 72.3%; mean age, 53)</td>
<td>Randomized controlled trial</td>
<td>Self-administered questionnaire survey</td>
<td>There were no significant differences in caring ability (knowledge, decision making and technical nursing procedure) between groups at baseline. After intervention, the intervention group scored higher on overall and three individual abilities, reported significantly higher caring ability improvement than controlled group. However, some participants in both groups were found to have inappropriate decision making behaviours, e.g., lack of awareness of helping patients with rehabilitation and self-care, deciding to carry out ADL for patients even though they were able to do independently.</td>
<td>Validity and reliability testing were not known.</td>
</tr>
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</table>
### Appendix 7 Characteristics of Studies on Cultural Influence on Health Care Decision-Making (n=14)

<table>
<thead>
<tr>
<th>First author, year of publication, country</th>
<th>Aim(s)</th>
<th>Sample (age, gender, ethnicity) and setting</th>
<th>Design</th>
<th>Data collection and analysis</th>
<th>Rigour</th>
<th>Results</th>
<th>Summary of major limitation</th>
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<tbody>
<tr>
<td>Bowman and Singer (2001) Canada</td>
<td>To explore attitudes of Chinese older people towards end-of-life decision making.</td>
<td>A purposive sample of 40 healthy Chinese older people in a Chinese community centre. (15 men and 25 women, mean age 73, age range 60-95)</td>
<td>Cross-sectional qualitative study</td>
<td>Semi-structured interview and constant comparative analysis</td>
<td>Expert checked the interpretation of data to enhance trustworthiness.</td>
<td>Participants based end-of-life decision making on various factors, e.g., respect for doctors and family, reflecting values of Confucianist traditions in Chinese culture. Some felt that doctor, in consultation with families, should make treatment decisions. Some trusted children’s decision making abilities and would leave decisions up to children when they became incapable. Many respondents didn’t want to name a proxy, and thought family conflict might happen due to disagreement between proxy and other families, consensus among children was important. 9 out of 12 doctors preferred to inform family first, and then whether, what, and how much the patient should be informed depended on families’ decisions. Patients had difference preferences. Some desired more autonomy. Some thought being cared for and having all decisions made by family made them happy. All patients reported their families made decision and signed informed consent form for surgery. This reflected the tradition of family autonomy in decision making in ancient China. The model guiding informed consent was ‘doctor-family-patient relationship’ model, where families make treatment decisions.</td>
<td>Participants came from one setting, with their attitude being influenced by Canadian health care system.</td>
</tr>
<tr>
<td>Cong (2004) China</td>
<td>To examine doctor-patient relationship and informed consent in China.</td>
<td>12 physicians working in different departments, 3 patients, and 3 family members recruited from a hospital in China.</td>
<td>Cross-sectional qualitative study</td>
<td>Interview</td>
<td>Not reported</td>
<td></td>
<td>Strategies for ensuring trustworthiness of data were not known.</td>
</tr>
<tr>
<td>Elwyn et al. (2002) Japan</td>
<td>To understand physicians’ experiences of cancer disclosure.</td>
<td>A purposive sample of 14 Japanese male physicians from medical, surgical, or radiological specialty areas of a hospital in rural area. (mean age 39, age range 25-48, mean years of working 15, range 4-23)</td>
<td>Cross-sectional qualitative study</td>
<td>Interview</td>
<td>Member checking.</td>
<td>Some participants (‘non-tellers’) usually didn’t tell patients cancer information, while others (‘tellers’) did tell. To avoid negative outcome of disclosure to patient, non-tellers firstly had discussion only with families and asked their preferences, which usually was not telling, and then doctors and families together decided not to tell patients truth. Non-tellers felt that disclosure was unnecessary and had negative impact on patients. It was suggested that in Japanese culture, families make decisions and further influence doctors’ decisions on cancer disclosure.</td>
<td>Rural location increased family participation, and decrease cancer disclosure. Small sample size and all male doctors.</td>
</tr>
<tr>
<td>Ganz et al. (2006) Israel</td>
<td>To explore end of life decision making in intensive care unit from a cultural perspective.</td>
<td>A consecutive sample of 363 adult Israeli patients who had died or received any limitation of life saving interventions from three ICUs, and was compared with a similar sample of patients from 37 ICUs in 17 European countries. (mean age 61.8±21, male 57%)</td>
<td>Prospective quantitative study</td>
<td>Patients’ types of end-of-life decisions received and demographic information were collected, and analyzed statistically</td>
<td>Not reported</td>
<td>A statistically significant relationship between end of life decision making and different regions existed. Israeli patients received withholding decisions almost twice as often as those in other European regions, but had much lower frequency of withdrawing decisions than their counterparts. It was suggested that according to Jewish ethics and law, the sanctity of life is important and prolonging of life is essential, so withdrawal of treatment is forbidden. In contrast, withholding treatment for terminally ill patient is allowed and viewed as a ‘passive non-interference’ in natural dying process in Israel. However, no ethical difference between withholding and withdrawing treatment was considered by cultures in some other religions.</td>
<td>No information about validity and reliability testing</td>
</tr>
<tr>
<td>Hattori et al. (2005)</td>
<td>To investigate older patients’ preferences</td>
<td>17 hospitalized older patients and 13 patients</td>
<td>Cross-sectional</td>
<td>Semi-structured interview</td>
<td>Member checking.</td>
<td>Most participants identified consideration of families as major factor influencing their wishes for end of life care. They wanted to die at home</td>
<td>Sample selection bias influenced</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Participants</td>
<td>Methods</td>
<td>Findings</td>
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<td>Japan and wishes for end of life care.</td>
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<td>who went to an outpatient clinic in Japan. (mean age 79.2, age range 67-88, female 23, male 7)</td>
<td>qualitative descriptive study</td>
<td>writing memo with families at bedsides, but concerned about burdening families with providing care, so some participants wanted to give up their expectation to die at their own homes. The findings emphasised family influence on Japanese patients’ end of life decisions.</td>
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<tr>
<td>Huang et al. (2003) the US</td>
<td>To investigate and compare socio-demographic characteristics and health status of older Chinese people newly admitted to a nursing home with those of residents from other racial/ethnic groups.</td>
<td>A consecutive sample of 258 residents aged 60 years or older (125 Chinese, 57 white, 53 Hispanic, and 23 black; mean age 82, 81, 79, 78 respectively; female percentage 58%, 53%, 34%, 48% respectively).</td>
<td>Cross-sectional quantitative study</td>
<td>Not reported</td>
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<tr>
<td>Humayun et al. (2008) Taiwan</td>
<td>To evaluate the extent to which doctors in Pakistan adhere principles of informed consent, confidentiality and privacy during outpatient consultation.</td>
<td>A random sample of 186 Pakistani patients in medical out-patient departments of two acute care hospitals (one public and one private hospital). (138 female, 48 male; mean age 35 range 13-79 in public hospital; mean age 38 range 12-79 in private hospital)</td>
<td>Cross-sectional quantitative study</td>
<td>Consultation was observed and recorded, pts were asked about perceptions on how drs followed principles of informed consent, confidentiality and privacy. Statistical analysis was used.</td>
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<tr>
<td>Liang (2002) Taiwan</td>
<td>To understand the care practice of caregivers of children with cancer.</td>
<td>34 family carers and 6 nurses from inpatient pediatric unit and outpatient clinics of a medical center in Taiwan. (majority of carer are female, aged 23-60; 6 female nurses aged 26-31)</td>
<td>Cross-sectional qualitative study</td>
<td>Semi-structured interview Carers' health care decision making for children was influenced by their cultural beliefs coming from families, older people or friends. Most carers decided to use traditional food therapy and traditional Chinese medicine to improve children’s body energy to deal with side effects of Western medicine, shared information about special folk therapy with friends who had similar experience, and monitored children’s condition during Western medical treatment to decide whether to use folk care as a supplement to Western medicine.</td>
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<tr>
<td>Ngo-Metzger et al. (2004) the US</td>
<td>To explore how Asian race or ethnicity influences patients’ health care experiences and satisfaction with care.</td>
<td>A stratified sample of 3,205 White-American respondents and 521 Asian-American respondents (Chinese, Filipino, Asian Indian, Japanese, Vietnamese, Korean), who were aged</td>
<td>Cross-sectional national survey, quantitative study</td>
<td>Telephone interview using questionnaire and statistical analysis Compared to white respondents, Asian Americans were more likely to report that the doctor did not involve them in decision making as much as they wanted. This might result from cultural difference in communication style between Asian and American people. Asian people often showed respect for doctors by nodding and smiling which were probably misunderstood as agreeing by doctors, and might not want to openly show their disagreement with doctors. Due to indirect communication style in Asian culture, patients might want to share their applicability of findings.</td>
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Non-representative sample influenced generalisability. Fewer items in outcome measures decreased
To explore the extent of congruence of knowledge, experiences, and preferences for DM on disclosure of diagnosis and prognosis between terminally-ill cancer pts and families.

Ruhnke et al. (2000) the US

A random sample of 273 Japanese physicians (mean age 47, male 87%), 58 Japanese patients (mean age 47, male 55%), 98 US physicians (mean age 46, male 72%), and 55 US patients (mean age 48, male 44%). Physiers were working in academic institutions/clinical settings, and pts were attending OPD.

Cross-sectional quantitative study

Self-administered questionnaire survey using 7 clinical vignettes, and statistical analysis

Pre-testing, translation and back-translation were conducted to ensure validity.

To compare the attitudes towards ethical decision making and autonomy from physicians and patients in Japan and the US.

At least 80% US physicians and patients, but only 17% Japanese physicians and 42% patients agreed a doctor should inform patients of cancer diagnosis firstly and then ask them decide whether family should be told. 80% Japanese physicians and 65% patients, but only 6% US physicians and 22% patients thought a doctor should inform families of cancer diagnosis firstly and then let them decide whether patient should be told. Across all decision situations, scores on patient autonomy for US participants were higher than those of Japanese groups, but scores on family and physician authority for Japanese groups were higher than those for US groups. The findings demonstrated cross-cultural differences, where US people favored patient autonomy, while Japanese people emphasized family authority and family-centred end of life decision making.

Takahashi et al. (2003) Japan

98 cases were out-patients who received influenza vaccination in a clinic of a hospital (mean age 71, female 7%), and 112 controls were non-vaccinated out-pts matched for physician and date of clinic visit in Japan (mean age 69; female 61%).

Retrospective case-control study

Telephone interview based on a questionnaire, and statistical analysis

Not pre-tested

To investigate the association between patients’ medical and personal characteristics and decisions of receiving influenza vaccination.

Major factors related to decision of accepting vaccination included recommendation by family and/or close friend, and having family and/or friends who had previous vaccination experiences. But patients in the US and some other Western countries usually made decisions on their own. The difference might be because in Japanese cultural tradition, family usually made decisions for patients, and trusting family and friends and maintaining harmonious relationship with them were considered as the most important.

Tang et al. (2006) Taiwan

A convenience sample of 617 dyads of Taiwanese patients (mean age 62, range 22-89, male 59%) and family caregivers (mean age 48, range 17-85, female 63) in 21 hospitals.

Cross-sectional quantitative study

Semi-structured interview and statistical analysis

Interview guide was validated.

To explore the extent of congruence of knowledge, experiences, and preferences for DM on disclosure of diagnosis and prognosis between terminally-ill cancer pts and families.

Cancer patients highly preferred physicians to inform them about diagnosis and prognosis than to inform families, and wanted physicians to inform themselves before disclosing any information to families. Taiwanese terminally-ill cancer patients demonstrated similar information needs as their Western counterparts in the UK and US, and this did not support the recognition that Chinese or Taiwanese cancer patients with Asian cultural background had different preferences of truth telling and left decisions up to families.
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Objective</th>
<th>Sample Characteristics</th>
<th>Methodology</th>
<th>Data Collection</th>
<th>Findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yap et al. (2004)</td>
<td>Hong Kong</td>
<td>To investigate ethical attitudes of doctors in intensive care unit.</td>
<td>65 doctors working in 11 intensive care units in Hong Kong. (male 40, female 25; 58 doctors under the age of 40)</td>
<td>Cross-sectional quantitative study</td>
<td>Self-administered questionnaire survey and statistical analysis</td>
<td>83% respondents involved patients or families when making decisions on limiting therapy, and 89% of respondents said patients or families should be involved in such decisions. But only less than half doctors in Europe involved patients or families in their decision making. The strong preferences for family participation in decision making reflected Hong Kong doctors’ respect for traditional Chinese cultural values, which emphasizes family values and families’ superior power in health care decision making for their patients.</td>
<td>Non-respondent bias influenced generalisability.</td>
</tr>
<tr>
<td>Yun et al. (2004)</td>
<td>Korea</td>
<td>To understand the attitude of cancer patients and families towards disclosure of terminal illness to patient.</td>
<td>A consecutive sample of 661 Korean participants (380 cancer pts and 281 families who have a relative with cancer) at 7 hospitals and 1 national cancer centre. (male pt 48%, pt mean age 50; male families 36%, family member mean age 43)</td>
<td>Cross-sectional quantitative study</td>
<td>Self-administered questionnaire survey and statistical analysis</td>
<td>Patients were more likely than families to want the patient to be informed of terminal illness, by the doctor, and immediately after the diagnosis. These findings are different from the recognition that Western cultural values which promote patient autonomy may not be universally applicable, therefore professionals need to explore patients’ wishes for decision making on truth telling. Different attitudes within the same culture may be due to patients’ and families' different roles and perspectives.</td>
<td>Non-representative sample influenced generalisability.</td>
</tr>
</tbody>
</table>
Appendix 8 Ethical Approval

Ms Yue Wang
PhD student
School of Nursing and Midwifery
University of Sheffield
16 June 2010

Dear Yue

Re: ERP 109: Older patients with stroke and their families: decision-making in an acute care setting in China

I am pleased to inform you that on 16 June 2010 the School’s Ethics Reviewers approved the above-named project on ethics grounds, on the basis that you will adhere to and use the following documents that you submitted for ethics review:

- University research ethics application form
- Project protocol
- Participant consent form
- Information sheet for patient and family
- Information sheet for health professional

The reviewers made the following comments and suggestions:

The study is well justified and well described and the information sheets and consent forms for patients and staff cover most of the possible outcomes. However the protocol does not really recognise the potential for distress of participants. Discussion about decision-making may well lead to a discussion about the circumstances of the stroke and its consequences, which is likely to be painful and possibly distressing for some participants and the researcher should be aware of and acknowledge this possibility.

In addition, although the consent form states that participation is voluntary and that withdrawal would not have any negative effects, we wonder if a clear statement (for patient and family participants) that it would not have any effect on any care and/or treatment might be preferable. This could also
be reflected in the information sheet which currently refers to penalties and no effect on benefits, which could be a little confusing for people as it stands. Researcher should consider amending the consent form and information sheet in light of this comment/suggestion. This should be done in consultation with supervisor.

If during the course of the project you need to deviate from the above-approved documents please inform me. The written approval of the School’s Ethics Review Panel will be required for significant deviations from or significant changes to the above-approved documents. If you decide to terminate the project prematurely please inform me.

Yours sincerely

Jane Flint
Ethics Administrator

cc Professor M Nolan, supervisor
    Dr E Hanson, supervisor
    Ms B Penhale, ERP Chair
Appendix 9 Permission Letter

Permission Letter

Ms Yue Wang
School of Nursing and Midwifery
The University of Sheffield
Samuel Fox House
Northern General Hospital
Herries Road, Sheffield S5 7AU
United Kingdom

Dear Ms Wang,

I write to inform you that you are allowed to engage in the project named below in XXX Hospital in Tianjin:

**Project Title:** “Older Patients with Stroke and Their Families: Decision-Making in an Acute Care Setting in China”

**Investigator(s):** Ms Yue Wang, PhD Student, School of Nursing and Midwifery, The University of Sheffield

**Supervisor(s):** Prof. Mike Nolan, Sheffield Institute for Studies on Ageing, School of Medicine and Biomedical Sciences, The University of Sheffield
Dr. Elizabeth Hanson, Faculty of Health, Social Work and Behavioural Sciences, Linnaeus University

**Location of Study:** XXX Hospital in Tianjin

**Duration:** 2 years

Yours sincerely,

(signature in Chinese and English)

Ph.D., Professor
President, XXX Hospital in Tianjin, P. R. China
Appendix 10 Information Sheet for Patient and Family

1. Research Project Title: Older Patients with Stroke and Their Families: Decision-Making in an Acute Care Setting in China

2. Invitation paragraph
You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to ask me or contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

3. What is the project’s purpose?
I am a PhD student in the School of Nursing and Midwifery at the University of Sheffield. I am carrying out a study to explore how older people who have had a stroke and their families make decisions whilst in hospital. Stroke is a major public health concern in China and worldwide, and is mainly a disease of older people. Following an acute stroke, older people and family carers often have to make major life decisions in a relatively short period of time. However, most of studies on the experiences of decision-making of older patients with stroke and their families have been undertaken in Western countries. Given the influential role of Chinese culture in health care decision-making, I am interested in exploring the experience of decision-making of Chinese participants, which may be different from those in other populations.

4. Why have I been chosen?
The Director of the neurological department to which you or your relative was admitted has identified you as someone who may be interested in taking part in this study, therefore now I am inviting your participation. If you are interested in the study, you can ask the Director to give your name to me. Then I will approach you and give you more information about the study and I will be able to answer any questions that you have. In total about thirty older patients with stroke and their family members will be recruited to the project.

5. Do I have to take part?
It is entirely up to you to decide whether or not to take part. Taking part in the research is entirely voluntary and refusal to participate will involve no penalty or
loss of benefits to which you are otherwise entitled. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form). Even though you have agreed to take part, you can discontinue participation or withdraw at any time either temporarily or permanently, without it causing any penalties or affecting any benefits that you are entitled to in any way. You do not have to give a reason.

6. What will happen to me if I take part?
If you agree to take part in the study, we will meet at a time and place of your choice and talk for about an hour about your experiences of making decisions about your care and treatment, for example, how do you make decisions, what types of decisions do you make. In order that I can have a full and accurate record of our conversation I would like to ask your permission to use a tape recorder. However, if you don’t want me to use the tape recorder, please just let me know and I will take notes during our discussion. You will be free to choose not to answer or talk about any questions or topics, and be free to stop the interview at any time. I would like to talk to you on more than one occasion. After our first interview I will send you a summary of our chat and ask if you agree with my description. After you have been discharged I would like to talk to you again about six weeks following discharge either face to face or over the telephone, to ask you whether you have any new experiences of making decisions since we first spoke. Also at the end of my study, if you agree, I will send you a summary of the major findings for your comments. Any travel or other costs will be paid.
As part of my doctoral study I would also like to carry out periods of observation on the ward where you or your relative are staying, and look at processes or events in which decisions might be made. I will ask your permission to observe. The observation will likely take place during the day and will involve me accompanying staff when they carry out care activities and attending ward round, case conference, or discharge meeting. The interviews and observation on the ward will take place over a two to three week period.

7. Will I be recorded, and how will the recorded media be used?
The audio recordings of the interviews made during this research will be used only for analysis and for illustration in publications, conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original data. No names will be used and it will not be possible for anyone to recognise any of the quotes that may be used.
8. **What do I have to do?**
Taking part in this study does not involve any restrictions or changes to your usual routines and lifestyle.

9. **What are the possible disadvantages and risks of taking part?**
There are no serious disadvantages and risks involved in your decision about whether or not to participate in this study. Some of the conversations may involve private or emotional topics such as the health conditions leading to the admission and during hospitalization, and your experience with the different aspects of health care services which are provided to you. You may feel slightly anxious when discussing feelings or thoughts associated with these topics. However, you will be free to choose not to respond to any questions, and also free to stop the interview or the tape recorder at any time. This will not affect the care or treatment that you or your relative is receiving here.

10. **What are the possible benefits of taking part?**
Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will have important implications for health and social care practice. By participating in this research you and other participants will be contributing to an increased and in-depth understanding of the experiences of decision-making of older patients with stroke and their families during their acute hospital stay. The findings will help to ensure older patients with stroke and their families receive high quality health and social care which can meet their needs and improve their quality of life.

11. **What if something goes wrong?**
Should you wish to raise a complaint during the research process, please contact:
Dr. A, the director of the neurological department, XXX Hospital, telephone number: 022-xxxxxxx.
Furthermore, if you feel your complaint has not been handled to your satisfaction by the director, you can contact Dr. B, the vice-president of XXX Hospital, telephone number: 022-xxxxxxx.

12. **Will my taking part in this project be kept confidential?**
All the information that we collect about you during the course of the research will be used for research purposes only and be kept strictly confidential. Your identity, and the identity of the persons, places and events about which you speak will be
protected by the use of code names. You will not be able to be identified in any research reports, writing, or publications arising from this research. All the tapes and relevant information (such as transcripts) about your identity will be stored in a locked file with access restricted to the researcher only.

13. What type of information will be sought from me and why is the collection of this information relevant for achieving the research project’s objectives?
Based on the information obtained from the interviews and observations about your experiences of making decisions during your or your relative’s hospital stay, we can learn to understand and inform other older stroke patients’ and their family members’ decision-making experiences in the future. Furthermore, we hope that the findings from an analysis of this information will then enable us to try to 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.

14. What will happen to the results of the research project?
I will use your account of your experiences and information obtained from the observations to prepare a written report and also a thesis for my PhD. You will have the opportunity to read and comment upon this report in order to make sure that I have interpreted what you have said and your behaviour correctly. In addition, the results are used solely for research purposes, and are likely to be published in professional and scientific journals after the study is completed, and you can obtain a copy of the published results from the researcher if you so wish. However, everything you tell me and information obtained from the observations will be treated as confidential and you will not be identified personally in any reports or publications arising from the study. The research findings will be reported to health professionals and their educators, in order that they can help older patients with stroke and their families to make effective decisions.

15. Who is organising and funding the research?
The research is carried out by a PhD student, Yue Wang of the University of Sheffield. The interview cost will be funded by the Research Training Support Grant, which is awarded to her by the University of Sheffield.

16. Who has ethically reviewed the project?
This project has been ethically approved via the ethics review procedure of The School of Nursing and Midwifery at the University of Sheffield. The University’s
Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

17. Contact for further information
Please contact me for further information: Ms Yue Wang, PhD student, School of Nursing and Midwifery, The University of Sheffield, Samuel Fox House, Northern General Hospital, Herries Road, Sheffield S5 7AU, United Kingdom. My telephone number is 07909012987.
I can be also contacted by telephone in Tianjin China: 13072040240 if you would like to talk to me when I am not in the hospital.
You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.
Appendix 11 Information Sheet for Health Professional

1. Research Project Title: Older Patients with Stroke and Their Families: Decision-Making in an Acute Care Setting in China

2. Invitation paragraph
You are being invited to take part in a research project. Before you decide if you would like to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to ask me or contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

3. What is the project’s purpose?
I am a PhD student in the School of Nursing and Midwifery at the University of Sheffield. I am carrying out a study to examine experiences of making decisions with older patients with stroke and their families from the perspectives of a variety of participants, including health professionals. Stroke is a major public health concern in China and worldwide, and mainly a disease of older people. Following an acute stroke, older people and family carers often have to make major life decisions in a relatively short period of time. However, most of studies on the experiences of decision-making with older patients with stroke and their families have been undertaken in Western countries. Given the influential role of Chinese culture in health care decision-making, I am interested in exploring this topic from Chinese participants’ points of view, which may be different from those in other populations.

4. Why have I been chosen?
The Director of the neurological department in which you are working has identified you as someone who may be interested in taking part in this study, therefore I am now inviting you to participate. If you are interested in the study, you can ask the Director to give your name to me. Then I will approach you and give you more information about the study, including the chance to ask any questions you might have. In total about thirty health professionals will be recruited to the project.
5. Do I have to take part?
It is entirely up to you to decide whether or not to take part. Taking part in the research is entirely voluntary and refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form) but you can still discontinue participation or withdraw at any time either temporarily or permanently, without it causing any penalties or affecting any benefits that you are entitled to in any way. You do not have to give a reason.

6. What will happen to me if I take part?
If you agree to take part in the study, we will meet at a time and place of your choice and talk for about an hour about your experiences of making decisions with older patients with stroke and their family members, for example, how decisions are made and what types of decisions are made. In order that I can have a full and accurate record of our conversation I would like to ask your permission to use a tape recorder. However, if you don’t want me to use the tape recorder, please just let me know and I will take notes during our discussion. You will be free to choose not to answer or talk about any questions or topics, and be free to stop the interview at any time. You may need to participate in the interview more than once, and for about one hour each time. First, we will have a discussion and I will give you some information about what we have talked about to see if you agree with it. And also at the end of my study, if you are interested, I will send you a summary of the major findings for your comments, or we may have a further discussion face to face, via the telephone, or via a group discussion. The travel costs will be paid if necessary. As part of my doctoral study I would also like to carry out periods of observation on the ward where you are working, and look at processes or events in which decisions might be made. I will ask your permission to observe. The observation will likely take place during the day and will involve me accompanying staff when they carry out care activities and attending ward round, case conference, or discharge meeting. In order not to influence your behaviour, I will not tell you when I will observe, and it could be anytime during your work. However, I will not be making judgements about quality of care but looking at how decisions are made. The interviews and observation on the ward will take place over a two to three week period.

7. Will I be recorded, and how will the recorded media be used?
The audio recordings of the interviews made during this research will be used only for analysis and for illustration in publications, conference presentations and
lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

8. What do I have to do?
Taking part in this study does not involve any restrictions or changes to your usual routines and lifestyle.

9. What are the possible disadvantages and risks of taking part?
There are no disadvantages and risks involved in your decision about whether or not to participate in this study. Some of the conversations may involve emotional topics such as the difficulties you have encountered when making decisions with older patients with stroke and their families. You may feel slightly anxious when discussing feelings or thoughts associated with these topics. However, you will be free to choose not to respond to any questions, and also free to stop the interview or the tape recorder at any time. This will not affect your work here.

10. What are the possible benefits of taking part?
Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will have important implications for health and social care practice. By participating in this research you and other participants will be contributing to a more in-depth understanding of the experiences of making decisions with older patients with stroke and their families during their acute hospital stay. The findings will help to ensure older patients with stroke and their families receive high quality health and social care which can meet their needs and improve their quality of life.

11. What if something goes wrong?
Should you wish to raise a complaint during the research process, please contact: Dr. A, the director of the neurological department, XXX Hospital, telephone number: 022-xxxxxxx.
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12. Will my taking part in this project be kept confidential?
All the information that we collect about you during the course of the research will be used for research purposes only and be kept strictly confidential. Your identity, and the identity of the persons, places and events about which you speak will be
protected by the use of code names. You will not be able to be identified in any research reports, writing, or publications with this research. All the tapes and relevant information (such as transcripts) about your identity will be stored in a locked file with access restricted to the researcher only.

13. What type of information will be sought from me and why is the collection of this information relevant for achieving the research project’s objectives?
Based on the information obtained from the interview and the observations about your experiences of making decisions with older patients with stroke and their families during their hospital stay, we can learn to understand and inform other health professionals’ decision-making experiences in the future. Furthermore, we hope that the findings from an analysis of this information will then enable us to try to help health professionals to make effective decisions in partnership with older patients with stroke and families, in order to provide high quality health and social care which best meets their needs and improves their quality of life.

14. What will happen to the results of the research project?
I will use your account of your experiences and information obtained from the observations to prepare a written report and also a thesis for my PhD. You will have the opportunity to read and comment upon this report in order to make sure that I have interpreted what you have said and your behaviour correctly. In addition, the results are used solely for research purposes, and are likely to be published in professional and scientific journals after the study is completed, and you can obtain a copy of the published results from the researcher if you so wish. However, everything you tell me and information obtained from the observations will be protected as confidential and you will not be identified personally in any reports or publications arising from the study. The research findings will be reported to health professionals and their educators, in order to facilitate them to make effective decisions with older patients with stroke and their families.

15. Who is organising and funding the research?
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I can be also contacted by telephone in Tianjin China: 13072040240 if you would like to talk to me when I am not in the hospital.
You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.
Appendix 12 Participant Consent Form

Title of Research Project: Older Patients with Stroke and Their Families: Decision-Making in an Acute Care Setting in China

Name of Researcher: Yue Wang

Participant Identification Number for this project: Please initial box

1. I confirm that I have read and understand the information sheet dated explaining the above research project and I have had the opportunity to ask questions about the project.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. Contact number of researcher: +86-13072040240

3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.

4. I agree for the data collected from me to be used in future research

5. I agree to take part in the above research project.

____________________   __________________   __________________
Name of Participant    Date                    Signature
(or legal representative)

____________________   __________________   __________________
Name of person taking consent    Date                    Signature
(if different from lead researcher)
To be signed and dated in presence of the participant

Yue Wang
Lead Researcher
To be signed and dated in presence of the participant

Copies:
Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project’s main record (e.g. a site file), which must be kept in a secure location.
## Appendix 13 Socio-demographic Characteristics of the Participants
*(patients, n=19)*

<table>
<thead>
<tr>
<th>Participant No.</th>
<th>Gender</th>
<th>Age</th>
<th>Marital status</th>
<th>Profession</th>
<th>Diagnosis</th>
<th>Stroke incident</th>
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</thead>
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<td>Male</td>
<td>60</td>
<td>Married</td>
<td>Bank clerk</td>
<td>Ischemic cerebrovascular disease, Diabetes</td>
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<td>2</td>
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<td>65</td>
<td>Married</td>
<td>Retired teacher</td>
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<td>1</td>
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<td>Married</td>
<td>Retired engineer</td>
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<td>Married</td>
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Appendix 14 Socio-demographic Characteristics of the Participants  
(carers, n=28)

<table>
<thead>
<tr>
<th>Participant No.</th>
<th>Gender</th>
<th>Age</th>
<th>Relationship of participant to patient</th>
<th>Profession</th>
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<td>Teacher</td>
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<td>Teacher</td>
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<td>Worker</td>
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<td>Retired teacher</td>
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<td>Daughter</td>
<td>Worker</td>
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<td>Male</td>
<td>63</td>
<td>Husband</td>
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<td>28</td>
<td>Female</td>
<td>45</td>
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<td>Saleswoman</td>
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## Appendix 15 Socio-demographic Characteristics of the Participants

(professionals, n=25)

<table>
<thead>
<tr>
<th>Participant No.</th>
<th>Participant interviewed</th>
<th>Gender</th>
<th>Age</th>
<th>Years of experience</th>
<th>Education level</th>
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</table>
Appendix 16 Interview Guide for Patients and Carers

1. What is decision-making?

2. What types of decisions are made by you or professionals (where/in what context)?

3. Who is usually involved in decision-making?
   Who is decision-maker?
   What is your role in decision-making?
   Who plays the main role, and what factors influence this?

4. What are your attitudes towards patient or carer participation in decision-making?
   What are the benefits or disadvantages of patient or carer participation in decision-making?

5. What are your experiences of making decisions (making choices)?
   Would you please talk about how you make decision in your everyday life?
   Would you please talk about how you make decision with regards to your/your relative’s health?
   Would you please talk about how you make decision regards to your/your relative’s current hospital treatment?
   Would you please talk about how you make decision regards to your/your relative’s current stroke?
   Can you give me an example of when you have made a decision about your/your relative’s medical treatment (together with your family)? Can you tell me about it, starting from the beginning?
   What are the processes of decision-making?
   What types of strategies are used when making decisions?
   What is the outcome of decision-making?

6. What are the strategies which facilitate you to make decisions?
   Patients’, carers’ or professionals’ strategies

7. What are your preferences for participation in decision-making?
   What are the similarities or differences between your preferences for and actual experiences of participation in decision-making?
   How much (if at all) do you like to be involved in decisions that affect your/your
relative’s health?
(E.g., asking patient: there are some people who like to leave decisions about their medical treatment entirely up to their family and the doctors, whilst there are others who like to make decisions together with their family, and then there are those people who prefer to make the final decisions themselves, how would you best describe yourself?)

8. What factors influence decision-making?
- Factors influencing patients’ or carers’ actual experiences
- Factors influencing patients’ or carers’ preferences
- Factors influencing decision-making outcome
- Facilitators of patient or carer participation in decision-making
- Inhibitors of patient or carer participation in decision-making
- Patient-related factors
- Carers-related factors
- Professional-related factors
- Environment-related factors
- Decision-making situation-related factors
- Role of culture in decision-making

9. What is the level of agreement on decision-making between patients, carers, and professionals?

10. Sensitising concepts:
- Negotiation
  - What is negotiation?
  - What is role of negotiation in decision-making?
  - How does negotiation affect patient or carer participation in decision-making?
  - What factors influence negotiation when making decisions?
- Participation/involvement
- Partnership
- Temporal dimension (difference of making decisions at different time)
- Trust
- Culture
  - Family
  - Interdependence
  - Relationship
Appendix 17 Interview Guide for Professionals

1. What is patient or carer participation in decision-making?

2. What types of decisions are made by you, patients or carers (where/in what context)?

3. Who is usually involved in decision-making?
   Who is decision-maker?
   What is your role in decision-making?
   What are role of patient and carer in decision-making?
   Who plays the main role, and what factors influence this?

4. What are your attitudes towards patient or carer participation in decision-making?
   What are the benefits or disadvantages of patient or carer participation in decision-making?

5. What are your experiences of making decisions (making choices) with patients or carers?
   Can you give me an example of when you have made a decision with your patients or their carers? Can you tell me about it, starting from the beginning?
   What are the processes of decision-making?
   What types of strategies are used when making decisions?
   What is the outcome of decision-making?

6. What are the strategies which facilitate patients or carers to make decisions?
   Patients’, carers’ or professionals’ strategies
   What are the strategies which facilitate you to make decisions with patients and carers?

7. What are your perceptions of patients’ or carers’ preferences for participation in decision-making?
   What are your preferences for making decisions with patients and carers?

8. What factors influence decision-making?
   • Factors influencing patients’ or carers’ actual experiences
   • Factors influencing patients’ or carers’ preferences
   • Factors influencing decision-making outcome
Facilitators of patient or carer participation in decision-making
Inhibitors of patient or carer participation in decision-making
Patient-related factors
Carers-related factors
Professional-related factors
Environment-related factors
Decision making situation-related factors
Role of culture in decision-making

9. What is the level of agreement on decision-making between patients, carers, and professionals?

10. Sensitising concepts:
   - Negotiation
     - What is negotiation?
     - What is role of negotiation in decision-making?
     - How does negotiation affect patient or carer participation in decision-making?
     - What factors influence negotiation when making decisions?
   - Participation/involvement
   - Partnership
   - Temporal dimension (difference of making decisions at different time)
   - Trust
   - Culture
     - Family
     - Interdependence
     - Relationship
Appendix 18 Field Notes of Interview

Participant Code Dr. #6
Interview Date 10/08/2010  Starting Time 9:30 am  Ending Time 10:50 am

Pre-interview goals for interview:
To collect information about the experiences regarding making decision with older patients with stroke and their family carers.

Location of interview: a meeting room

People present: the researcher and the participant

Description of environment:
This was a small meeting room in a hospital building which provided a relatively quiet and private environment for the conversation.

Nonverbal behaviour:
Sometimes when talking about the experiences of making effective decisions with patients or carers and helping patients have a good recovery, the participant was very happy and laughed. Sometimes he needed to stop a couple of seconds to think about how to answer the question.

Verbal behaviour:
Sometimes he tried to find the appropriate words to describe his experiences. When he didn’t quite sure what I meant by a certain question, he initatively asked me to give explanation.

Researcher’s impressions:
Generally speaking, the participant was very interested in the interview topics, and replied very confidently and actively. The overall communication was going smoothly.

Important points during the interview:
When asking about the influencing factors, I should keep in mind or write down all of the factors mentioned by the participant. Then after he talked about a certain factor, I could remind him to continue explaining others left if he forgot other points that he just listed and mentioned about.
When the participant felt difficult to explain some points, or gave relatively abstract answers, I asked him to give examples. Whenever I felt unclear about the meaning of the participant’s description, I asked him to elaborate on those points.

Technological problems:
The interview stopped for about several minutes during the telephone interruption, and was also interrupted for about two minutes when a staff member came to the office to look for somebody.
Appendix 19 Field Notes of Observation

Date: 29th, July, 2010  
Time: 8:30 – 10:30 am  
Activity: ward round  
Participants: seven doctors and the researcher  
Total number of beds (patients): 21  
Total number of stroke patients: 13 (61.90%)

**Decision-making during ward round**

**Patients or carers decided to follow doctor’s advice.**

**Bed #1** The doctor suggested the patient to stop smoking, then the patient said that he would follow the doctor’s advice and stop smoking.

**Bed #8** The doctor told the patient that he could discharge the day after tomorrow, suggested him to go to outpatient clinic for his haematological problem, and explained to the carer about the patient’s blood test result. The patient and carer agreed with the doctor’s advice. Then the doctor continued to provide information to both of them about taking medication and participating physical activity at home. When talking about issues such as blood test and medication treatment, the doctor tried to use simple language, but still it seemed that it was difficult to understand some of her explanations where she used medical terms.

**Bed #12** The carer told the doctor that the patient removed his gastric tube at night. The doctor suggested that they inserted a new gastric tube again and restrained the patient's hands. Then the carer said ‘yes, absolutely.’

**Patients or carers disagreed with doctors’ advice.**

**Bed #6** The carer told the doctor that her patient’s condition was getting better. The doctor suggested that they would give the patient rehabilitation and acupuncture therapy. But the carer refused to give the patient rehabilitation, and said that because the patient once had a bone fracture and injury in his leg, therefore it was not appropriate for the patient to receive rehabilitation. The doctor agreed with the carer’s decision, suggested that they only gave acupuncture therapy to the patient, and advised the carer to help the patient move his leg to facilitate recovery.

**Bed #13** Given the patient’s current serious condition, the doctor suggested a tracheotomy for the patient, and asked the carer to decide whether or not to accept
the treatment. The doctor also explained the purpose of having a tracheotomy and why sputum aspiration had not been able to solve the patient’s problem. The carer said: ‘the patient has diabetes, which, I am afraid, may have effect on his wound healing’. The doctor said that this was not the major problem, and it might be difficult for the patient to withdraw the tracheotomy tube.

However, the carer said that they decided not to give tracheotomy to their patient. The doctor said: ‘if we don’t give tracheotomy, the patient may have the risk of life threatening condition when the sputum obstructs the respiratory tract. If you decide to refuse the tracheotomy, you need to sign a refusal of treatment form, and then the best treatment for the patient would be sputum suction and nebulization therapy’.

It seems that for the carer’s decisions which may lead to the patient’s life threatening or emergency conditions, the carer needs to give their signature to indicate that he or she would like to take the responsibility for the potential poor outcome.

**Bed #17** The patient felt that she had recovered and didn’t want to stay in the hospital, so she asked the doctor whether she could discharge today. The doctor said: ‘you had better stay here today for one more day, we will observe your condition, and if there’s no problem, you can discharge tomorrow.’ But the patient still insisted to leave the hospital today, so the doctor finally agreed to her decision.

**Patients made decisions.**

Patients mainly made decision on diet, for example, what type of food they would like to eat for breakfast, lunch and supper. Sometimes, it was their carer who initiatively asked for and followed the patient’s advice on his or her preferred diet; sometimes, it was the patient who actively took this decision-making role. Interestingly, during the ward round, one nurse came up to a doctor and told her that a patient wanted to stop her oxygen therapy and remove the oxygen equipment. The doctor said that ‘Yes, we can stop her oxygen therapy’. It seems that patients can participate in making some decisions on non life-threatening issues to a certain extent, for instance, a patient in stable condition can decide whether or not to continue using oxygen therapy.

**Doctors decided to hide the poor diagnosis from the patient.**

**Bed #20** The doctor asked the carer to come to her office after ward round to talk about the patient’s condition. They didn’t talk to each other in front of the patient during ward round. She told the carer that the patient might have a highly suspect gastrointestinal cancer and brain metastases, and would consult doctors in
gastrointestinal department for further examination and diagnosis. She said that she couldn’t explain the purpose of a certain kind of blood test (cancer screening) to the carer in front of her patient, since she didn’t want the patient to know that she may have got cancer.

The carer cried and asked whether the doctor could give some medication to control the patient’s pain, then the doctor agreed to her request. The doctor further emphasised the importance of not telling the patient’s about the possible cancer diagnosis. She told the carer that if the doctor in gastrointestinal department wanted the patient to have some examinations, the carer should lie to the patient, and tell the patient that the reason why she needs the examination is that she has a poor appetite. The doctor suggested that both doctors and family members should not tell her the truth in order not to make patient feel anxious and stressful.

**Other interesting observations**

Male patients usually had male carers, e.g., the son, but none of whom were sons-in-law. Female patients usually had female carers, like daughter or daughter-in-law. A staff member told me that this was perhaps because it was convenient for carers to look after patients with the same gender.

When doctors did their ward round, the carers often stayed at the bedside of their patients. The doctors spent most of their time communicating with the carers, asking carers about patients’ health condition, disease progress, and current situation. Especially for stroke patients, quite a few of them had more or less difficulties or problems with their speaking or expression, or had conscious disturbance, like coma. Therefore patients were not able to describe their symptoms or discomfort, to express their feelings or opinions, or to indicate whether or not they agree with or accept doctors’ advice or recommendations.

But sometimes I also found that, although they had speaking problems, stroke patients could understand what doctors had said to them, in particular, when doctors carried out physical examination for the patients, they could follow doctors’ instructions and perform some kinds of movement, like making a fist, or lifting the tongue. Another example was a stroke patient with aphasia, who could answer doctor’s question about whether he had headache by closing his eyes which meant ‘yes’, and by shaking his head which meant ‘no’.

If the patient didn’t lose his or her ability to speak, he or she could tell the doctor his health problems. For example, a male patient, who was a retired teacher, could give very clear and detailed description about the changes of his condition to his doctor during ward round, therefore his wife, namely the carer, only gave a little
input. For instance, he spoke clear Mandarin and explained how his pain was like, the location of his pain, the date and time the pain started, and the situation in which his pain was getting worse.

In most cases, patients and carers often consulted doctors on a variety of issues, like the purpose of examination or treatment, patient’s diet or nutrition, patient’s activity, or what to do after discharge. The doctor had a lot of patience, and gave very detailed, comprehensive and individualised explanations. For example, a patient would discharge from hospital soon, the doctor gave the patient and her carer the advice on the patient’s diet, medication, exercise, activity, rehabilitation, follow-up, prevention of recurrence, and how to get doctor’s help if needed.
## Appendix 20 Transcripts and Codes

**Date/Time:** 11:00-12:00 am 13/10/2010  
**Venue:** patient’s room  
**The interviewer:** YW  
**The participant:** C

<table>
<thead>
<tr>
<th>Line</th>
<th>Content</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>YW: Would you please share with me your experience of making decisions, starting from the beginning, like what happened at the time of getting sick?</td>
<td>Identifying early symptoms</td>
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<tr>
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<td>Son: Yes. On the 3rd of October, after my mother had her lunch, at about 2:00 pm, you know, singing is one of her favourite hobbies, so she started sing a song. At that time, I found that there was something wrong with her singing, as well as her speaking, obviously something wrong. I also asked my wife to come to take a look at my mother’s situation, and she came to us, then we noticed that something went horribly wrong, my mother couldn’t speak normally, couldn’t speak smoothly and fluently, then we immediately took her to the specialised hospital for neurological disease by car.</td>
<td>Informing wife</td>
</tr>
<tr>
<td>3</td>
<td>YW: Why did you go to that hospital?</td>
<td>Quickly taking patient to hospital</td>
</tr>
<tr>
<td>4</td>
<td>Son: Because we live close to that hospital, so we directly drove her to that hospital. You know, at that moment, based on my observation of my mother’s problems, I thought she had got a cerebral infarction, because my father once suffered from cerebral infarction, so I know clearly that this is an emergency condition and it's very important to get timely medical treatment, so I wanted her to be able to immediately get thrombolytic treatment at that time, and therefore we went to that specialised hospital for treatment.</td>
<td>Living close (proximity)</td>
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<td>5</td>
<td>After we got to that hospital, the doctor said that since this lady had a very old age and multiple complications, they were not able to solve her health problems, and so he suggested us to transfer the patient to either of two hospitals, including the General Hospital and the current one. We contacted both hospitals by telephone, and then came to the current one since there were no beds available in the General</td>
<td>Making judgement on patient’s condition, family history, understanding gained through past experience (source of knowledge)</td>
</tr>
<tr>
<td>6</td>
<td></td>
<td>Quickly getting treatment</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td>Suggesting different alternatives</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>Checking availability</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td>Choosing hospital (making default choice)</td>
</tr>
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Hospital. So my mother was admitted to this department in the evening on the 3rd, and then received a series of examinations.

YW: Did your mother ever suffer from a stroke?

Son: In terms of her disease history, the most severe brain disease which she had ever had is the carbon monoxide poisoning. She was 47 years old, and suffered from serious cerebral oedema which was the sequela of her poisoning at that time. I remember that she was in a coma for 40 days, and had been hospitalised for treatment for four months before she fully recovered from her disease. She is 82 years old now, and this is the second time she demonstrates brain cell-related symptoms.

YW: So you mean she hadn’t had a stroke in the past?

Son: No. In my family, my father once had cerebral infarction, but my mother had carbon monoxide poisoning in middle age when she was 47 years old, so I think in terms of caring for patient with brain cell-related disease, three children, I mean my younger brother, younger sister and I, pay greater attention to three important issues.

YW: Yes, more detailed explanation please.

Son: The first one is that the patient with brain cell disease doesn’t cooperate with you, especially when you need to help her take oral medication. So I need to figure out which strategy to use to successfully administer medication to her. The second issue is how to prevent her from suffering bed sore, because she may stay in bed longer than usual. And the third important thing is related to her psychological recovery. So I would like to introduce to you our experiences of caring for my mother in terms of the three aspects.

Firstly, helping her taking oral medication is difficult, especially at the key stage when she or her sensation recovers to a certain degree. I remember that when she suffered from carbon monoxide poisoning at the age of 47, she was admitted to a Traditional Chinese Medicine hospital and needed to take Chinese herb medicine for treatment. It’s very difficult to deliver the medication to her at that time, so when preparing the medication, I had to boil the herb medication until it condensed to a

<table>
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<tr>
<th>Patient’s disease history</th>
<th>Patient’s past treatment experience</th>
</tr>
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<tbody>
<tr>
<td>Family history</td>
<td>Understanding gained through past life experience (source of knowledge)</td>
</tr>
<tr>
<td>Deciding how to help patient take medication</td>
<td>Deciding how to prevent bed sore</td>
</tr>
<tr>
<td>Deciding how to prevent bed sore</td>
<td>Making decision relevant to psychological care</td>
</tr>
<tr>
<td>Deciding how to help patient take medication</td>
<td>Patient’s disease history</td>
</tr>
<tr>
<td>Patient’s past treatment experience</td>
<td>Past life experience of caring for patient (giving medication)</td>
</tr>
<tr>
<td>small amount of decoction.</td>
<td>Past life experience of caring for patient (giving medication)</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-------------------------------------------------------------</td>
</tr>
<tr>
<td>Then when delivering the concentrated decoction, because she had normal sense of taste, so I used the fruit juice to help her take the medication, for example, giving one spoon of pineapple juice, then giving one spoon of medication, and after that giving another spoon of pineapple juice, or sometimes I used orange juice to help successfully administer medication to her. I think because my mother still had normal chewing and swallowing functions, but just didn’t had very normal consciousness level, so although her sense of taste allowed her to know that she was taking bitter medication, she still could successfully take the oral medication with the fruit juices.</td>
<td>Deciding how to help patient take medication</td>
</tr>
<tr>
<td>During the current hospital stay, yesterday we found it very difficult for her to take a certain powdered medication, so we had to help her take it with her meals. Today we ask the doctor whether we can deliver this medication with yogurt, and the doctor says that using yogurt to give medication is not good for patient because the yogurt can influence the pH level of the drug. So now we need to figure out how we help her take the medication at noon today, for example, taking the medication with lunch, so I have to try my best to successfully give the medication to my mother.</td>
<td>Asking doctor</td>
</tr>
<tr>
<td>I am also thinking that, for example, whether we can give the medication with water in which we add some honey to improve the taste, but you know, since her blood sugar level is a bit higher than normal, so we need to make sure that the method which we choose doesn’t have negative impact on her blood sugar level.</td>
<td>Doctor answering/explaining</td>
</tr>
<tr>
<td>Daughter: I think taking medication with meal is better than taking medication with yogurt for the patient’s treatment and recovery.</td>
<td>Trial and error for medication</td>
</tr>
<tr>
<td>YW: Plain boiled water is more suitable, according to the doctor.</td>
<td>Deciding how to help patient take medication</td>
</tr>
<tr>
<td>Daughter: But we can do nothing about it. I know clearly that the patient will have better treatment effect if she takes medication with plain boiled water rather than with food, but what can I do, it is almost impossible for her to take the medication with water. I think at least she can benefit from the treatment effect of the medication to a certain degree if she takes it with her meal.</td>
<td>Quite complex reasoning</td>
</tr>
<tr>
<td></td>
<td>Thinking holistically before making decision</td>
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<tr>
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<td>Choosing the least worst option</td>
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Anyway, I think, there are two difficulties of caring for this kind of patients, one is giving medication, and the other one is giving them water to drink. You know, when caring for my father who once also had cerebral infarction, I asked him to drink water when he sat up on the bed, but he always refused. And finally, since I just could do nothing about it, so I had to allow him to lie flat in the bed and then gave him water. And I thought, it’s impossible for him to get enough water only through receiving IV infusion, right, given the large amount of water which he needed.

YW: Right. It’s impossible for the patient to always get water only by receiving IV infusion.

Daughter: in addition, he had hemiplegia, and was also unable to suck water properly with drinking straw. So, finally, after trying all the methods to solve the problem, I decided that I allowed him to lie in the bed, then I gave a very small amount of water each time, in case that he suffered from coughing and choking. Especially, at the later stage of his stroke, we also allowed him to lie in the bed and then helped him eat food, because it’s difficult for him to sit up and then eat and swallow the food. And we used the similar method to deliver the oral medication to him at that time.

YW: These are important experiences.

Daughter: Yes. Unlike us, he was unable to finish these activities normally. But I think it is easier for us to care for my mother than to care for my father, since she doesn’t have a very serious stroke.

Son: The second important issue of caring for patients with neurological disease is to prevent bed sores, because these types of patients generally all need to stay in bed due to their severe condition, and are very likely to develop bed sores or even infections. So we all work very hard and actively carry out various caring activities, such as applying hot compress, washing the patient to keep her skin clean, turning the patient frequently and assisting her to pass urine and stool. We have a bed at home whose function is very much similar to that of a special toilet seat, and is particularly useful and convenient for her to pass urine and stool. So we all try to...
provide the best possible care to my mother.
The last important point is the recovery of her psychological condition, and I think we have figured out a so-called 'psychological treatment' and plan to deliver it to my mother after she discharges from the hospital. What is the psychological treatment? I find that our parents are both very old, and have a very common characteristic related to their memory, which is that, older people remember events of long ago better than recent events.

Therefore, since my mother is very interested in singing, so I think we will give singing therapy to her. She can sing a lot of different old songs, and we have various old songs CD or DVD at home. And I know that she may not be able to successfully sing the full song at the very beginning after discharge, but I believe that her condition may get improved gradually, and she may be able to sing the whole song after practicing for a period of time, and this will indicate that her brain function has recovered.

YW: You can know how well her brain function has recovered.
Son: Right. For example, if she can sing two sentences in a song today, and three sentences tomorrow, and four the day after tomorrow, so this means that my strategy is helping her gradually recover from her disease, or this is motivating, how to say, maybe I can say, this is activating her brain cells? In addition, I think this strategy can be helpful for her overall or holistic recovery.

Another method to facilitate her recovery is to go out for sightseeing. I believe that if you can look at and enjoy those beautiful scenes, you will have a very happy mood, especially when you always live in an urban city and you feel like you are under a lot of pressure. So I think I will take her out for sightseeing, take her to the countryside to broaden her views, and meanwhile, she can also enjoy the fresh air. I think, for the purpose of her good recovery, going out is much better than staying at home.

YW: You know a lot about caring for older patient with stroke, would you tell me how you gain these experiences?

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Son: I think there are two prerequisites for gaining experiences of caring for the patient. One is the love, you need to love her and really care about her. I don’t think we are very successful in our work or career, but I can say we have a very successful family life, and again, one important prerequisite for this is that family members love each other very much.

In the past, when my mother was seriously ill, we were all very young, and I was only 20 years old at that time. I remember that people always asked my mother why her children were so nice to her and all came to look after her, my mother attributed it to her family education for her children. I think she is a very successful mother who gives us a very good family education, and this is also the reason why we make great efforts to care for and help her today. Of course she also loves us very much.

YW: Yes.

Son: This is the first important thing, I mean, the love is the first important thing, and my love to my mother allows me to try my best to look after her, and to think about how to solve the problems which I have encountered, for example, the way of giving oral medication to my mother by using fruit juice. Actually I can’t find or get this information from books or other reading materials, so I mainly gain these experiences in my practice. Of course, I need to try many times before I can find the most appropriate way of giving medication to my mother, rather than gain success at the first attempt. These care strategies are very much suitable for her specific disease condition.

YW: Yes, suitable for her specific characteristics.

Son: Meanwhile, we treat her like a kindergarten child rather than an adult, and this means that we need to take her specific condition into consideration when caring for her. For example, now she doesn’t have the adult-level IQ or thinking ability, so when you talk to her, you can’t treat her like an undergraduate student, but you need to consider her as a kindergarten kid and then give her explanations or information. So gradually as time goes by, her IQ may get recovered or improve step by step, then we need to make adjustment to our way of communication or caring methods.
accordingly.

YW: You do all these things because you love your mother.

Son: Yes, three of us all love her very much, and always encourage her to actively receive treatment and fight against her disease. I think we need to give her more encouragement rather than criticism or blame.

The second important thing is to get information or knowledge about caring for the patient. I feel that I have become half a doctor after I spend such a long time looking after my mother, for example, caring for her when she was sick in the past as well as during her current hospitalisation. A long time ago when people didn't have access to the internet, I very much would like to read books to gain more medical knowledge or information. After I gain lots of knowledge, when I communicate with health professionals, doctors, there will not be a huge gap between both of us. Otherwise, if there is a huge knowledge gap between you both, I am sure that they will not be willing to talk with you.

And more importantly, because it is you who spend much longer time staying with and caring for your patient at her bedside than the doctor, so you can provide all the information about patient’s condition to the doctor, right?

YW: Yes.

Son: Although I don’t know which treatment should be given to the patient to solve her problem, telling doctor the patient’s condition can provide him or her more information which will be taken into consideration by him or her, or be used as evidence to make accurate diagnosis. Again, for example, after she takes medication, what’s the change of her condition, what’s her treatment effect, I will give this information to doctors. I think by doing so, I can establish an interaction with health professionals, which are good and helpful for patient’s treatment.

I think as a family carer, I need to closely work together with health professionals, we are like one person, such a kind of relationship will be extremely beneficial for patient’s treatment. So I think I need to establish an interaction with doctors and nurses. In addition, I will also timely tell health professionals about the good needs.)

Loving relationship between family members
Making decision relevant to psychological support
Getting care related information/knowledge
Seeing himself as an expert carer, drawing on expertise based on long term experience of caring for patient (source of knowledge)
Getting information from book (source of knowledge)
Having equality with professionals
Gulf in knowledge between professionals and lay people influencing communication
Seeing himself as an expert carer, drawing on expertise based on long term experience of caring for patient (source of knowledge)
Providing information
Providing information for making diagnosis
Providing information for making treatment plan
Providing information for assessing recovery
Building relationship through interaction
Closely working together as one
Building relationship through interaction
Relationship building as a strategy
progress which they have made in order to improve or enhance their confidence, for example, timely telling them the positive change or improvement of patient’s condition, or the effectiveness of treatment.

So that’s why I would say the interaction between carers and health professionals is very important, and both of us need to work closely with each other, we are just like one person, and we blend into one entity. It’s totally not like a kind of relationship in which I come here to give money to you, and you provide treatment to me. Health professionals and carers both share a common goal which is to provide effective treatment for patient and solve his or her problem, or cure his or her disease, we both have the same purpose, so we need to work together and integrate into one entity.

YW: Just now you said that you could get information or knowledge of caring for the patient from the internet, do you have any other sources which you can search to get related information?

Son: I have read some books which introduce the related information. I feel like I consider caring for the patient as a major research topic, this is an important research topic which I always think about in my mind. So if I have some questions to ask, I will try to get the answer or information, for example, from the internet, which is extremely fast, so I can quickly get the information which I need.

YW: Right, very convenient.

Son: Yes, if I have something which I don’t understand, or if I have got questions, I can immediately search the internet, and then quickly get related information.

YW: Next, I am wondering, in your mother’s current hospitalisation, do you mainly come here to look after her?

Son: Yes, over the last couple of days, both my younger brother and sister have been very busy, and therefore don’t have enough time to come here to look after my mother, so I always stay in the hospital and take care of her. I think, as the oldest child in the family, I need to take responsibility for everything that happens in our family, and in order to help my mother get effective treatment and good recovery, and I need to try my best to overcome all the difficulties which we may encounter.
YW: Who usually cares for your mother at home?
Son: At home, since three of us all need to work and are always very very busy, so we hire a helper to look after my mother, and give the helper instructions on how to care for her. And recently I moved back to my parents’ home and stayed with them because they are not in good health, and it’s also very convenient for me to instruct the helper to provide care for my parents and manage their health problems.

YW: Since your mother was admitted, what other decisions have you also made?
Son: When my mother was admitted, the doctor had given us very clear and detailed explanations on her condition and her health problem that had occurred. At that time, I thought that the most important thing was to make accurate diagnosis, so I decided to try our best to cooperate with doctors to accept various types of examinations needed for my mother. I didn’t think that there was a need to consider the cost, or to consider how much money we need to spend, our main purpose was to give systematic and sufficient examinations to my mother.

YW: Does your mother have health insurance?
Son: Yes, she has health insurance.

YW: Do you have the experience in which doctors need to ask for your consent before referring your patient to a certain type of examination?
Son: I think, in terms of giving consent to examinations for my mother, I have a principle, I will definitely accept all the examinations which are suggested by doctors, no matter the cost is covered by her health insurance or the cost needs to be paid by using our own money. I will accept all the exams for my mother without any hesitation.

YW: So you don’t think about how much the examination will cost.
Son: No. I always believe that the more the doctor knows about the data or information about patient’s condition, the more accurate his or her diagnosis or decision will be. Otherwise, if the doctor only has the inadequate information about patient’s condition, or has incomplete understanding about patient’s health problem,
he or she will make an inaccurate diagnosis. So we never need to discuss and take
the issue of cost into consideration when making decisions on examinations for my
mother.
When making other decisions, such as which family member will come to the
hospital to look after my mother, we may have a discussion to decide how to make
an arrangement for taking on caring responsibilities.
YW: Are there any other things that doctors require you to give consent?
Son: On the day when my mother was just admitted to this department, doctors
immediately gave a critical condition notice and asked me to give my signed
consent. At that moment, I was really unwilling to give my consent, since I didn’t
think that her condition was very serious to a critical degree, and didn’t think her
condition was that terrible. The doctor explained to me that the disease of stroke
usually had a 7-10 day development period, so it’s very difficult to anticipate or
estimate the future progress of the disease, although we could see that currently my
mother only had problem with her speaking and communication, we didn’t really
know what would happen during the next 7 to 10 days.
After the doctor taught me the knowledge which I didn’t understand before, I
thought I should accept the reality that my mother was in a very unstable and critical
condition, and should give my consent and cooperate with doctors. Because I think
everybody, both doctors and carers, have a common goal, which is to do good to the
patient, to do anything in the patient’s best interest. Although we play different roles,
we have the same goal.
YW: What about making decisions on treatment for your mother?
Son: In terms of decisions about my mother’s treatment, so far there haven’t been
any decisions that we need to make, and there also hasn’t been any consent
regarding giving medication which we need to give to doctors. However, I think, if
the doctor suggests that my mother needs to receive certain treatment or medication,
we will definitely accept his or her suggestion. We will accept all of their
suggestions or advices, since I believe that all of their suggestions or advices must

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| Cost is no object |
| Sharing care with family |
| Having a discussion within family |
| Being required to give consent |
| Disagreeing with doctor |
| Giving explanation |
| Giving consent, cooperating with doctor |
| Sharing a common goal, in patient’s best interest |
| Same goal different role |
| Making few treatment decision |
| Accepting doctor’s treatment advice |
| Trusting doctors/their advice |
be helpful and beneficial for my mother’s treatment or recovery. So that’s why we
don’t think that the issue of cost will have any negative influences on her treatment.
I think that, to ensure my mother to have a good recovery and to regain the good
quality of life is the most essential goal, which must be borne in mind when we
make decisions.
YW: Do you make any decisions related to your mother’s nursing care here in the
hospital?
Son: We accept all of nurses’ advices if they are helpful for my mother’s recovery.
YW: Yes, and do nurses ask you to decide which hand they can use to give IV
infusion to your mother?
Son: Yes, they do ask me to decide using which hand to give IV therapy. I usually
say ‘it’s up to you, you can use the hand where it is easier for you to find the suitable
blood vessel and to perform the IV infusion’. But some younger nurses don’t have
enough experiences with or skill of performing IV infusion, and often can’t
efficiently perform the IV infusion, and can’t make her IV infusion to be successful
at the first attempt, so they may need to try it several times. So in this case, we
always encourage rather than criticise the nurse.
YW: They are not skilled in performing IV infusion.
Son: Under these circumstances, I think I should give more encouragement to the
nurse. Since we have already come to the hospital for treatment, so we should try
close to establish good relationship with the health professionals, and to cooperate
closely with them. Of course, every carer wants nurses to be able to successfully
perform IV infusion at their first attempt, rather than to try several times, but you
can’t control their behaviours or performance, right? Meanwhile, if you say you
don’t want a particular nurse to perform IV infusion for your patient, I think this is
not good for that nurse, who then perhaps will be criticized or blamed by other
people.
YW: You have talked about the interaction between you and doctors, so as a family
carer, could you explain what the relationship between both of you is?
| 314 | Son: I think, the relationship between doctors and carers, is much like, both of us are an integrated entity, one person, we work closely together as a holistic entity, rather than a separate individual or party, I mean, not like, you belong to this party, but the patient and I belong to that party, no like that. Our relationship is actually like, we are a unified entity, although we may play different roles or look at things from different perspectives. |
| 315 | YW: You once mentioned that you both share the common goal. |
| 316 | Son: Yes, we have the same goal, although we play different roles, we’ve got the same purpose which is to cure the patient’s disease. |
| 317 | I think after the patient is admitted, we need to start to closely work with health professionals as soon as possible by using two strategies. Firstly, you need to rely on them rather than disagree with or get into conflict with them. You also need to respect them, really follow their advices and conscientiously act out those advices. |
| 318 | Secondly, you need to quickly improve your medical knowledge level, and immediately search different sources to get necessary information or knowledge. |
| 319 | You need to particularly pay attention to the extent to which you consult health professionals when you have questions or something you don’t understand. For example, after they give you the explanation of a certain issue, don’t immediately ask them once again if you are still unclear about some of their explanation, and don’t repeatedly bother them with too many questions again and again, as they are very busy in their work and don’t have enough time to answer your questions. |
| 320 | Being an integrated entity |
| 321 | Working together rather than separately/alone |
| 322 | Being an integrated entity, different roles, different perspectives |
| 323 | Same goal different role |
| 324 | Working together with professionals |
| 325 | Relying on rather than disagreeing with professionals |
| 326 | Respecting professionals, following their advice |
| 327 | Getting care related information (source of knowledge), searching different sources, |
| 328 | Asking professional questions |
| 329 | Giving explanation |
| 330 | Not to question professionals unless necessary |
| 331 | Establishing rather than destroying good relationship (harmony) |
Appendix 21 The Development of the Category ‘Patients'/carers’ Seeking Process’

Patients’/carers’ Seeking Process

Process of searching

- Searching for medical help
  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.
  Patient(8)1: I got numbness in my hand, then immediately after I found this problem, I decided to come to this hospital for treatment…I was admitted to this department.
  Carer(15)1: When we came back and found that our mother lay on the floor…we immediately dialled 120 to call an ambulance…and sent her here for treatment.
  Carer(10)2: He had a convulsion and coughed up phlegm at night, I guessed that there was something wrong with his lung in addition to his cerebral infarction…I called 120 for ambulance service and timely sent him to A & E of this hospital for treatment.

- Searching for hospital
  Patient(10)2: I went to the general hospital…stayed at A & E for treatment…next morning I left there and went to the specialised hospital…since there was no bed available…and a poor-organised environment in the general hospital although it’s located closely to my home…when I got to the specialised hospital…there was no bed again…I needed to stay at A & E for treatment and wait for bed…I just couldn't wait any more…so I came to the current hospital…and was admitted.
  Carer(20)1: We sent the patient to 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.

- Searching for health-related information
  - Using mass media (e.g., reading books/newspaper/magazines, watching TV programs, searching on the internet)
    Patient(2)4: My wife very much enjoys watching TV programs which talk about the way of keeping a healthy life style.
Patient(10)3: When the doctor prescribed medication…I often read some books in order to understand the treatment effect of the medication.

Carer(10)4: My father often made newspaper cuttings every day in order to provide me the knowledge and information related to the way to keep in good health.

Carer(6)5: Caring for patient is an important research topic…if I’ve got questions, I will immediately search the internet to quickly get related information.

- Accessing staff (e.g., doctors or nurses)
  Nurse(17)6: Carers may ask us about post-discharge care, and ask about how to provide care for their patient after discharge.
  Patient(10)8: During ward round, I heard that doctors talked about why I needed to take a certain medication…I enjoy listening to their discussion or explanations during ward round, since I can gain a lot of knowledge from doctors.
  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(11)14: I ask doctors about my mummy’s treatment effect…her progress…what they will do next, what the step forward is…I also ask nurses…how many bottles of fluids will be given to patient by IV infusion…ask about the medication change…the treatment.

- Consulting patients with similar disease or going through similar procedure
  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 similar disease…about their experiences of receiving treatment.

- Talking to medical students
  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.

- Using their own network or personal contacts
  Doctor(3)16: Carers may consult other people, like friends, or ask the friends who are doctors to help them make decisions…ask for other people’s advice or
opinions.

Doctor(5)2: Patients or carers may consult other relatives or friends who are health professionals…to help with their decision-making.

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 them questions and learn from them about how to look after an older patient.

- Attending training

Patient(10)6: I try to well manage my own disease and keep in 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.

Process of watching/comparing

- Watching other patients’ or carers’ behaviours

Patient(12)11: Dr. L kept asking the patient in bed #2 which is next to my bed about his diseases which he once had in the past, but only recently, he told Dr. L that he once also had pancreatitis…The doctor then said that why he didn't tell the doctor earlier about his disease history…I also know that, there was another patient who had stayed here for more than 10 days, but doctors still were unable to make an accurate diagnosis…but his wife was very anxious to have the patient discharged back home…I also feel that some patients here in this neurological department are not willing to attend physical activities or walk around.

Carer21(3): 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.

- Watching and comparing situations of themselves and those of others

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 Dr. H 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. Carer(10)8: I also 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.

- Watching professionals’ behaviours
Patient(11)9: Before I go to bed, 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/carers in the corridor, they just turn off the lights; and on the contrary, if there are still somebody in the corridor, they will turn off the lights a bit later, and this makes it very convenient for patients/carers to finish what they are doing…they 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… their management is very good based on my close and careful observation.

Process of checking

- Checking with patients
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.

- Checking with doctors
Doctor(1)7: Some patients may have a little medical knowledge, but don’t trust the doctor… they may go to other hospital to consult other doctors about their examinations or treatment.
Doctor(5)2: Some carers would like to repeatedly check with doctors the information or explanation given by them, and to look at whether doctors consistently give the same answer. This is perhaps partly due to their distrust in doctors. They may even ask and check the information with different doctors and hope that they can know about different opinions and make better decisions.
Nurse(19)3: When patients don’t trust doctors, they will be suspicious about doctors’ advice or explanations. Some patients 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.

- Checking on the internet
Doctor(1)7: Some patients may have a little medical knowledge, but don’t trust the doctor…They may search the internet to check whether what doctor said is correct.
Appendix 22 Theoretical Propositions Emerging from Interview Data

Preliminary theoretical propositions in relation to the concept of ‘trust’

The factor of trust figures prominently in patients’, carers’ and professionals’ decision-making experience, and perhaps could be categorised based on different types or objects of trust. Conditions necessary for trust to develop and consequence of trust seem to vary from situation to situation.

Patients/carers trust in hospitals

- If patients/carers trust a hospital, they will be more likely to decide to come to this particular hospital for the patients’ treatment.
- If carers trust a hospital, they may also decide to come to this particular hospital for their own health problems.
- If patients/carers don’t trust the current hospital, they may perhaps decide to transfer the patient to another hospital for treatment.

Patients/carers trust in professionals

- It seems that the more patients/carers trust a doctor, the more likely they are to:
  - decide to see this particular doctor
  - cooperate with the doctor
  - ask for and follow the doctor’s advice
  - have better compliance
  - give signed consent
  - leave decisions up to the doctor
  - put their patient in the doctor’s hands
- It is also possible that the more patients/carers trust doctor, the more likely they are to actively participate in decision-making.
- If patients/carers don’t trust a doctor, they may perhaps:
  - repeatedly check with the doctor the information or explanation given by him or her to look at whether the doctor consistently gives the same answer
  - question the doctor’s advice
  - consult other doctors
  - consult other patients with similar health problem
  - consult other relatives or friends with medical background
  - hesitate to make decisions
  - make decisions on their own rather than follow the doctor’s advice
Patients trust in carers

- The carer whom the patient trusts the most is likely to be the decision-maker.
- If patients trust carers, they perhaps would like to
  - follow carers’ advice
  - leave decisions up to carers
- If patients don't trust carers, they may not trust carers’ explanations.

Patients/carers trust in traditional Chinese medicine (TCM)

- If patients/carers trust in TCM, they will be more likely to decide to:
  - choose to take TCM medications
  - receive acupuncture therapy
  - invite a TCM doctor to attend a consultation for patient (seeking second opinion)
  - be transferred to TCM hospital for treatment and rehabilitation
  - go to TCM hospital for treatment after discharge

Patients/carers trust in information

- Patients/carers may trust information from different types of sources, such as
  - online information which is consistently provided by big websites
  - information delivered in TV program presented by national or municipal level TV stations
  - information/explanation directly given by doctors rather than passed by others

Professionals trust in patients/carers

- It seems that if doctors trust patients/carers, they will be more likely to develop a good relationship and work together smoothly.
- Professionals’ willingness to provide detailed and clear information may be influenced by their perceived trustworthiness of carers (or sometimes patients):
  - if the doctor thinks that patients/carers are worth trusting, he or she may perhaps tailor the information by giving more information about more effective or radical treatment intervention although it may have risks associated
  - if the doctor doesn't trust patients/carers, he or she may tailor the information by giving more information regarding conservative treatment or the safest treatment which however may not be the most effective one
Conditions necessary for trust to develop between professionals and patients/carers

- Skills of creating trust used by both staff and patients or more likely carers include:
  - giving detailed and clear explanation on progress or prognosis of disease
  - having lots of patience
  - being confident
  - answering questions
  - knowing patient very well
  - respecting each other
  - allowing patients/carers to spend time talking about their concerns
  - providing effective treatment
  - providing standard and professional treatment intervention
  - establishing harmonious relationship between professionals and patients/carers
  - frequently communicating with patients/carers
  - maintaining long term engagement and frequent contact between each other
Appendix 23 Operational Memo

Date: 20th August 2011

Important methodological issues during 2nd phase field work

Adjustment made to the interview guide

Originally in the interview guide, before moving on to explore with participants decision-making with regards to their health, I started off broadly by asking the choices or decisions made in people’s everyday life before their hospitalization, in order to establish a pattern of everyday decision-making or a family pattern of decision-making. And when pattern of decision-making on ward was generated, I could compare the changes and differences.

But during the data collection process, this didn’t usually work well. For example, even if I started the interview by asking about decision-making in daily life, the participants quickly shifted their focus to the current hospitalisation/admission experience. Then during the following discussion, sometimes they voluntarily talked about decision-making pattern in their daily life, or I deliberately raised these types of questions. It seemed that patients/carers were very interested in sharing their experiences of health care decision-making related to either stroke currently or patients’ other types of health problems, such as diabetes or hypertension.

When talking about the current experience of getting stroke and receiving treatment during hospitalisation, they would like to start from what happened at the very beginning, for instance, what happened at the onset of stroke or at the time of getting sick. So I decided to start the interview with the question ‘Can you tell me about the event’s leading up to your or your patient’s admission/hospitalisation?’

As advised by Mike, asking this type of question is appropriate and can allow the participants to set the direction of the interview. I then can follow the leads that the participants provide, that is to say, I will be led by what participants want to let me know. Meanwhile, participants often would like to tell their story in a logical way or according to a temporal order, this helps me understand the social process in their decision-making experiences.

Another consideration is that, the interview with patient/carer was usually quite short and lasted about 30 or 40 minutes, and sometimes patients/carers initiatively suggested stopping the interview before all questions or areas were covered due to perhaps carers’ lack of time or patients’ tiredness given acute nature of their condition. So I think it would probably be better to directly raise the topic related to health care decision-making at the beginning in case that if I ask about general decision-making style firstly, I may not have enough time to invite questions
regarding stroke or health care related decision-making experiences.

**Interview technique**

During the interview, sometimes I communicated with participants about my own experience of making health related decisions and those of my family members. This is also a way of working with participants guided by constructivist principle. For example, I once shared with participants my experience of making decision with my mother when she had stroke, and the decision-making experience of my father-in-law during his hospital treatment for stroke, in order to help the conversation go smoothly and successfully. Mike warned that when giving information about myself to my participants, I needed to be very careful that I didn't give the impressions that my information or what I was saying to them was the only standard or correct answer. I should allow the participants to openly share their own experiences or stories.

During the interview, patients/carers may 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 during hospitalization, and their experience with the different aspects of health care services, which may be painful and possibly distressing for some participants. Here Mike suggested that, in addition to allowing them to freely choose not to respond to any questions or stop the interview at any time, I also needed to offer different types of support to my participants depending on the specific situation at that moment, for example, holding their hands, patting on their shoulder, asking their concerns or difficulties, or asking the need to pass these information to staff. I think this not only is the requirement of ethical principles, but also can help me establish good relationship with participants.

**Issues for further exploration in the next set of interviews**

When I re-enter the field for the second time, I will follow up a few interesting topics with the participants in order to gain a more in-depth understanding on these issues, such as:

- Professionals’ seeking behaviours, e.g., recognising and seeking patients’/carers’ knowledge or experience
- Professionals’ sharing behaviours, e.g., actively attempting to share their own knowledge or experience with patients/carers
- Impact of the idea that ‘patient’s happy mood results in good recovery’, e.g., leading to tailoring and hiding behaviours
• Role of rehabilitation, e.g., how rehabilitation and its introduction influence decision-making
• The extent to which carer actively involves patient in making medically related decisions
• Role of cost, e.g., whether the cost of the subsequent treatment and its health insurance coverage may possibly determine the choice of the prior examination
• Potential impact of quality of ward environment, e.g., how to prioritise a couple of determining factors of choice of hospital such as staff expertise, hospital locality, and quality of physical environment
• Potential positive emotions about decision-making, e.g., carers feeling sense of satisfaction when making decision out of their filial piety

**Theoretical sampling criteria**
During the 2nd phase data collection, I will use theoretical sampling not only to recruit participants, but also to select events or situations for my observation. For example, I plan to interview different types of participants including:
• Patients/carers with poor background, e.g., people from rural area or laid off workers, to look at impact of cost
• Poorly educated participants, e.g., people from rural area or living in the country, to look at influence of education level
• Female patients/carers to look at gender difference
• Patients/carers from other regions to explore cultural difference in regional level
• Patients who have a stroke for the first time to explore the role of prior experiences of making health related decisions
• Physiotherapists to look at the role of rehabilitation

In addition, I will carry out more observation during the evening and night time, and mainly look at:
• Other types of decision-making role played by professionals, patients and carers
• How certain types of decisions such as when patients go to bed or when patients get up are made
• How staff on duty during evening/night shift and carers make decisions to handle patients’ emergency situations

It is possible that patients/carers who meet the theoretical sampling criteria come to the current hospital and department to seek medical help. However, the potential challenge is whether I will be able to find and get access to the different types of participants or events based on my theoretical sampling plan within the time constraints.
**Member checking**

Member checks should be a continuous and on-going process which happens throughout all phases of the study. During my 2nd phase field work, I will:

- Working with previous participants, e.g., trying to contact previous patients/carers by telephone and have a chat with them and ask their feedback for the major findings as a whole as well as the key findings from their particular individual interview

- Doing member checking with new participants
  - Making changes or adding new ideas into the interview guide, and then asking questions step by step to check emerging findings with new participants
  - At the end of interview rather than the beginning, presenting to participants some major findings which have not yet been mentioned by them for their comments
  - Sharing major study findings with other patients/carers/staff who aren’t formally interviewed and asking for their opinions
Appendix 24 Analytical Memo

Date: 1st July 2011

Initial ideas or preliminary findings from the analysis of interview with a patient

*Who are decision-makers or involved in decision-making:*

The patient is the major decision-maker.

*Factors influencing decision-making:*

Cost of treatment/examination (the patient participates decision-making involving the issue of cost.)

Patient’s financial condition (① cost is no object if patient has insurance; ② patients/carers with poor economic condition may not necessarily be concerned about the issue of cost.)

Nature of the hospital environment (a poor-organized and crowded environment can let patient decide to change hospital or transfer to another hospital.)

Distance between patient’s home and hospital (the patient chooses to go to the hospital which is located close to home.)

Reputation of hospital (① the patient chooses to go to the famous hospital with high reputation of good quality service and professional expertise; ② good reputation can help establish patient’s trust towards doctor and hospital.)

Working experience (job skill, patients’ profession) (① the patient’s understanding of hospital reputation gained from his working experience in a drug manufacturer helps him make choice among hospitals; ② experience of working with health professionals helps the patient establish the trust towards hospital and doctor.)

Having relatives who are professionals (this increases patient’s understanding about doctors and hospitals, which further help the patient build trust towards them.)

*Types of decisions being made by patient:*

Making judgment about health condition or problem at the onset of stroke.

Making help-seeking decision at the onset of stroke to get timely treatment.

Choosing hospital.

Transferring patient from one hospital to another.

Making decisions about examination which involves the issue of cost.

Not making treatment decisions, but following doctors’ advice on treatment.

Making decision about receiving rehabilitation.

Making decisions on diet, moving or walking around, doing functional exercises.
Keeping in a happy mood to facilitate recovery or maintaining harmony.
Choosing hand for IV infusion.
Following doctor’s advice about when to discharge.
Deciding to see a particular doctor and receive follow up treatment after discharge.
Going to community hospital to receive rehabilitation therapy after discharge.
Recommending own doctor to relatives with stroke.
Making adjustment to diet to manage diabetes.

**Role of trust:**

**Patient trust in hospital**
*Choosing a particular hospital demonstrates the trust towards this hospital.*

**Patient trust in doctor**
*If patient wants to have a good recovery, the first thing to do is to trust doctor.*
*Patients/carers should trust doctors and follow their advice.*

**Conditions under which trust can emerge**
*Firstly, I have the experiences of working and interacting with professionals.*
*Secondly, some of my relatives are health professionals, e.g., my aunt is a nurse, so I know something about doctors and hospital through talking to her.*
*Thirdly, the current hospital is a Level 3 Class A hospital, which provides high quality service, has professional expertise, high reputation, nationally recognised medical centres, and famous experts.*

**Doctors’ and patients’/carers’ trust in each other**
*Doctors and patients/carers trust each other, and only by doing so can patients/carers successfully make their decisions and have a good recovery.*
*I trust doctors and believe that they will provide effective treatment to me or to the patient, and meanwhile, doctors also trust me and believe that I will actively cooperate with them when receiving treatment, so this is a mutual trust between each other.*

**Key processes used by patient in making decisions:**
*‘Sharing’:*
*In terms of making decision on treatment, if patient has some ideas or requirements, he or she can have a discussion with his or her doctor, they both can talk about the pros and cons of the treatment, the doctor can give patient suggestions, and of course, patient has the right to have the final say or make the final decisions.*
You tell the doctor your opinions, and the doctor also gives you his or her suggestions, but finally you still need to make your own decisions.

‘Seeking’:
Asking doctors to give him IV medication instruction to read to understand treatment effect.
Reading books in order to understand the treatment effect of the medication.
Asking doctor to explain why patients all have cerebral infarction, but receive different IV medication.
Listening to doctor’s discussion or explanations on treatment during ward round in order to gain knowledge.
Seeking the hospital which the patient perceives as the most ideal and appropriate one (this key process is often accompanied by the consideration on or prioritisation of different influencing factors, such as the proximity, convenience, reputation, and quality of environment).

‘Watching’:
The patient is watching what happens to him as well as to other patients, recognising the similarities of their condition and differences between their treatment interventions, and then asking doctors for further explanation. ‘Watching’ seems to be part of ‘seeking’ behaviour.

‘Checking’:
The patient checks with other patients about their feelings when they go through the rehabilitation therapy process. This also seems to belong to a form of ‘seeking’ process.

Patient’s preference of making decisions:
- Patient prefers to accept doctor’s suggestions/advice on examination/treatment.
- Patients prefer doctors to make decisions on treatment (because they have lots of knowledge and expertise, but he is not a health professional).
- Patient should follow doctors’ advice/instructions or to act out their advice and do whatever they advise the patient to do.
  Following doctors’ advice on treatment is a very simple or easy-to-understand principle.
  Doctors take responsibility of my treatment, so they give me advice, therefore I must treat them with respect and take actions based on their advice.
Key processes used by professionals in making decisions:

‘Sharing’: Doctors/nurses give very clear and detailed explanation about the importance and purpose of a certain treatment or examination for patient to make decisions or give consent, e.g., giving clear explanation about the medication prescription. *Doctors do a very good job in giving explanation to patients when patients need to make decisions.*

If doctor can give more explanation to patient, patient will find it very easy to make choices, and will be very happy and satisfied with the treatment and care received. *Some patients are not able to be discharged after two week hospitalisation, doctors will tell them about their condition and why they need to stay for a few more days, and they often give very clear explanations.*

*Doctors tell patient about how to get the follow-up treatment, such as how to go to OPD for follow up and for getting prescribed medications.*

‘Seeking’: When I was admitted, after the doctor asked me about my disease history and knew that I had diabetes, she further asked me where I got treatment and what medications I had been taking.

Professional-patient/carer relationship (partnership working):

- Health professionals and patients/carers should cooperate with each other.
- Health professionals and patients/carers should understand each other.
- Health professionals and patients/carers should have mutual respect towards each other (if you respect your doctor, he or she will definitely respect you, this is a mutual respect between each other…this is demonstrated when the patient follow doctors’ advice or act out their advice and do whatever they advise the patient to do; or doctors take responsibility of patient’s treatment and give patient advice, therefore patient must treat them with respect and take actions based on their advice).
- Doctors and patients/carers trust each other (I trust doctors and believe that they will provide effective treatment to me or to the patient, and I or the patient would like to follow their advice; and meanwhile, doctors also trust me and believe that I will actively cooperate with them when receiving treatment, so this is a mutual trust between each other).

*Only by doing so (i.e., professionals, patients and carers understanding, respecting and trusting each other) can patients/carers successfully make their decisions and have a good recovery.*
Appendix 25 An Email from a Physician During Co-construction of Findings

Dear Yue,
Thank you very much for your email and the summary of interview and main findings. I have carefully read through the materials that you sent to me, and feel that I have learned a great deal from you through participating in your study. After looking at these interesting findings, I think that the cultural issue, as one of the factors influencing decision-making, is very important, and now I would like to share with you some of my understandings and add a couple of points for your consideration.

I think for some patients or carers, their decision-making behaviours during hospital treatment may perhaps also be determined or influenced by their religious beliefs. Religious beliefs can play an influential role in decision-making about whether or not to give dying patient invasive emergency interventions or whether or not to donate patients’ organs after their death.

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

Buddhists also think that during the first 7 days after death, they should try their best not to move the dead body of patient. But generally speaking, under our current health care system, dead patient will be cremated during the first 1 to 2 days after death. Therefore, to avoid this from happening, they will choose to allow their patient to spend the late stage of life staying at home and finally to die at home.

I don't know much about Christianity and Islam, so am not sure about how patients or carers who have these types of religious beliefs make decisions. However, based on my clinical experience, I know that some carers who are Muslims may also refuse to give invasive examinations or treatments to their dying patient, and request a discharge for their patient.

I believe that there should be some religious beliefs-related factors which exert the above influences on people’s decision-making behaviours.

Anyway, I hope this information helpful.
I wish you every success with your studies!

Dr. XLR
March 7th 2011
Appendix 26 Types of Decisions Made by Patients/Carers

Making decisions on diseases other than stroke (diabetes, hypertension, etc.) (life before stroke)

Making judgement about health problem, seeking medical help (at the time of stroke)

Choosing hospital, hospitalising patient, choosing doctor (on admission)

Making decisions during hospitalisation
- Examination/treatment
- Nursing care
- Rehabilitation
- Acupuncture
- Other issues
  --appointing proxy
  --paying cost
  --monitoring/reporting, caring for patient
  --sharing care with family
  --keeping healthy living style
  --taking responsibility for bad outcome

Stopping treatment; transfer to other hospital; satisfactory recovery

Giving up treatment or life support; choosing where to die

Patient discharges earlier than 2 weeks.
- Going home
- Going to other hospital

Patient goes home.

Patient dies.
- At home
- At hospital

Patient goes to nursing home.

Patient goes to other hospital for rehabilitation or acupuncture.

Making decisions at discharge
- Discharge or continuing to stay for treatment
- Requesting medication, exam, equipment
- Making after-discharge plan
  --where to place patient
  --preparing home environment
  --undertaking self-care
  --who cares for patient
  --providing long-term home care
  --receiving rehabilitation & acupuncture
  --follow up treatment (medication, IV)
  --keeping healthy life style
  --managing other diseases

Patient goes to other hospital for rehabilitation or acupuncture.
Appendix 27 Summary of Final Findings

Another chance to ‘have a say’.

Firstly, thank you very much for taking part in my study exploring the ways in which people with stroke, family carers and staff make decisions in an acute hospital setting. Your input into the interviews and observations has been essential in my gaining a fuller understanding of the process of making decisions and the factors that influence the decisions made.

I would now like to seek your knowledge and help again by asking you to comment on the results of the study. Below I briefly describe the main findings and would be very grateful if you could read these through and think about the following questions as you:

Do the processes and factors described ‘make sense’ to you and do you recognize them from your own day to day work?

Do the processes and factors described capture the main influences on decision-making or are there any important processes and factors missing?

Could these findings be used to help patients, carers and staff to make decisions more effectively? If so, how?

Could the findings be useful in the training of doctors, nurses and other staff?

Could they be useful in producing information/advice/guidance for patients and carers?

Do you have any other comments or suggestions on the findings from the study?

After reading the findings could you please email me your response to the questions above, which you can find again at the end of this document.
The study findings
The text presented below provides a brief summary of the main conclusions of the study based on numerous interviews with staff, patients and family carers, together with many periods of observation and conversation with the above groups. The findings indicate that during the period of 2-3 weeks that patients with acute stroke are in hospital that patients themselves, family carers and staff are involved in making many, often complex decisions. The type of decisions made change over time, as does the degree of urgency and the time for decisions to be made. Some decisions are led primarily by professionals, others by family members and others are made between professionals, families and patients. The processes involved are therefore often quite complex. The main processes/factors are highlighted in bold below.

Despite the complexity of the situation, the study suggests that the most important goal for all groups during the patients’ journey through the hospital is to maintain ‘harmony and to create and maintain ‘harmonious relationships’. The concept of harmony operated at several levels such as ensuring that the patient had ‘internal harmony’ with respect to their overall feelings of well-being and of being in harmony with themselves and their situation as well as maintaining harmony in the various relationships and interactions that occurred between patients, their families and the professional staff at the hospital. The idea of harmony emerged as a key cultural dimension that was not only very important in Chinese society as a whole but also figured prominently in the health care setting. Several other cultural factors also operated at differing levels. For example, as suggested above at a national level, the notion of creating and keeping harmony was considered very important in ensuring good decision-making. At an ethnic level, a factor closely linked with maintaining harmony was the idea of keeping the ‘whole body’ of a dead person held by people with Hui nationality, carers therefore usually refused tracheotomy since they thought that it would disrupt the wholeness of the patient's body.

With respect to making treatment decisions the fact that in Southern China an older patients’ brothers/sisters, or in Northern China, children paid the cost and made decisions reflected cultural differences in a geographical sense.

Both families and professionals also tended to hold their own ‘cultural’ expectations for example about family members’ caring and decision-making roles or the patterns of communication that different medical teams adopted. Such behaviours usually had the aim of maintaining harmony within the family or the
multidisciplinary team. At personal level, some carers who held specific religious beliefs, such as Buddhists, felt that to die peacefully was very important and so they would refuse invasive or radical treatment/examinations.

Equally important in maintaining harmony and reaching agreed decisions was the role of trust. This again operated at several levels. For example, patients and carers usually chose a hospital which they trusted or where they trusted the doctors. The more patients/carers trusted doctors, the more likely they were to have better compliance or to leave decisions up to doctors. Those who had less trust were more likely to question doctor’s advice or consult other people (e.g., other doctors, relatives or patients). Similarly, the more the patient trusted the carer, the more likely he or she was to follow the carer’s advice or leave decision up to the carer.

Some patients/carers would place their trust in TCM and so choose to receive acupuncture therapy or TCM medication, or to be transferred to TCM hospital for treatment and rehabilitation.

Trust also influenced the way that professionals’ worked with patients/carers. For example, doctors might give more information about conservative treatment and highlight the risks associated with radical treatment if they didn’t trust patients and carers to make decisions about their treatment.

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

- Giving detailed information and clear explanation on progress or prognosis of disease;
- Having lots of patience;
- Being confident;
- Answering questions;
- Knowing the patient well;
- Respecting each other;
- Allowing patients/carers to spend time talking about health condition and their concerns;
- Providing effective treatment to improve patients’ condition;
- Providing the standard and professional treatment intervention;
- Communicating frequently and well with patients/carers;
• Maintaining long term engagement and regular and frequent contact between each other

Based on the above other behaviours intended to promote harmonious relationships included:

• The patient, family carers and professionals tried to maintain regular contact and to agree shared goals and mutual understanding by closely work together, to avoid conflicts, problems, blame or potential complaint.

• The main decision-maker often communicated with their extended family (e.g., spouse of the older patient or other relatives), particularly if there was a risk of blame, or if things might go wrong. In such circumstances advice, discussion and negotiation with other family members were more often used to reach an agreement or consensus, and to avoid conflicts, problems, or blame for the purpose of maintaining harmony between each other.

• In the medical encounter, patients/carers would pay particular attention to their way of communication to maintain harmony between them and professionals.

• During communication, staff members (doctors, nurses, physiotherapists) had a positive attitude towards the patient and carers, respected and smiled at them, listened attentively, leaned forward, kept eye contact, spoke slowly and clearly to allow them to understand, and allowed them time to finish their talking.

• In daily life, patients/carers decided to keep themselves in a happy mood or in harmony.

• Patients and carers took the quality of physical environment into consideration when making a choice about which hospital to go, and preferred a hospital which offered or provided a good quality physical environment, believing that a good quality physical environment enabled the patient to maintain a happy mood and harmony.

The following examples illustrate professionals’ or carers’ behaviours that either would encourage good communication and a harmonious relationship between the patient, carers and professionals or compromise a harmonious relationship.

More specific behaviours potentially promoting harmony included:

• Doctors talked with carers outside patient room or at doctors’ office about the patient’s severe or life-threatening condition due to their reluctance to tell the patient ‘bad’ news (see hiding below).
• Doctors directly communicated with the patient when the decision was about a minor problem, and allowed her to make her own decision.
• Nurses asked the patient or carer to choose which hand to use for IV therapy.
• Nurses allowed the patient or carer to choose their preferred time to start IV infusion.
• During ward round, when there was a need to introduce patient’s condition to doctors, carers asked the patient whether there were anything new or important to report.
• Fellow patients and their carers exchanged experiences of seeking timely medical help, receiving treatment/examination/physical therapy, or keeping healthy life style.

Behaviours potentially compromising harmony included:

• Doctors only communicated with carers during ward round, and so the patient was ignored, left out, and excluded from information provision and decision-making.
• During ward round, doctors had little communication with the patient or carers, had too much communication with colleagues or junior staff, or put too much emphasis or focus on teaching responsibilities.
• Staff members (doctors, nurses, physiotherapists) had little patience when communicating with the patient and carers, and so interrupted them while they were talking to doctors, made quick judgements about their topic or question, weren’t willing to repeat what they were saying, answered questions before the patient/carer had finished speaking, or spoke quickly rather than slowly.
• Staff members’ non-verbal behaviours suggested impatience and they made themselves unapproachable by avoiding eye-contact, looking away from the speaker, or frowning.
• During ward round, sometimes carers impatiently interrupted the patient when she wanted to talk to doctors directly, and so excluded the patient from decision-making.

**Information and knowledge** was another vital component of decision-making and this could come from a variety of sources, including:

• Specialised medical knowledge gained through communication with professionals
• Knowledge gained from mass media (e.g., TV, books)
• Knowledge gained from their own prior health care related experiences (e.g., managing diseases or caring for patients or using health care services)
• Knowledge gained from their working experiences, particularly in the case of men who were more likely to have and draw on job-related knowledge. For example, in daily life, the husband who was a warehouse manager was good at preparing and giving medication to the patient in a very careful and conscientious way and closely followed doctor’s instructions. As a hotel manager, the son-in-law was perceived as competent to make decisions and so played an active role in decision-making for the patient. The fact that he attributed good service to good management was perhaps also due to his job title.
• Knowledge gained from their relatives’ or colleagues’ experiences (e.g., managing disease or caring for patient or using health care services)
• Knowledge gained from their relatives who were health professionals
• Knowledge gained from other social network.

In order to make the best useful of information patients, carers and professionals used an extensive range of processes. The main ones are described below.

• **Seeking**
  - Patients and carers would use **seeking** behaviours when attempting to obtain or ask for medical help, finding out or looking for a suitable hospital, or searching for health-related information through accessing staff or using mass media. Doctors or nurses could also recognise and seek the patients’ or carers’ knowledge or experience.
  - Other processes which similarly reflected the nature of seeking included watching/comparing (closely related to exchanging) and checking.
    - **Watching/comparing** behaviours were mainly used by the patient, for example, who observed attentively what happened to them and to other patients and made a detailed comparison in order to identify the similarities or differences; or observed other patients’ behaviours carefully and closely in order to inform their own decisions.
    - Sometimes, the patient and carers used **checking** to verify or confirm the truth/accuracy/correctness of the information given by doctors through consulting a source or authority, for instance, with nurses, on the internet, or through their wider social network, e.g., consulting relatives or friends or neighbours who were health
professionals perhaps due to a lack of trust or lack of clear understanding.

- **Sharing**
  - Sharing processes were actively and widely used by patients, carers and health professionals. For example, both patients and family members shared information about her condition/treatment effect/outcome with doctors. Sometimes, family carers shared health-related experiences with other patients/carers. Doctors’ or nurses’ sharing behaviours were demonstrated by providing the patient and carers information about treatment and care.
  - Processes related to sharing included informing, advising, exchanging (closely related to watching/comparing), and tailoring/interpreting.
    - The patient informed her family about her condition at the onset of stroke, and then her family members informed other relatives about her condition and hospitalisation.
    - The patient and her carers gave health-related advice to other patients/carers.
    - Sometimes, the patient and other fellow patients sharing the same room would exchange experiences of disease or treatment. Patients, family members and other patients/carers might exchange comments about a certain doctor’s performance.
    - Tailoring/interpreting behaviour was commonly used by the carers and health professionals, but rarely by the patient. Tailoring involved altering or adapting information to meet a specific need. For instance, a carer might explain the meanings of doctor’s treatment plan or advice in a certain way in order to influence a patient’s decision. Professionals also used tailoring/interpreting processes. For example, doctors or more likely nurses would interpret scientific information in an easy-to-understand way. Doctors would selectively tailor or interpret information based on the trustworthiness of the patient or carers (e.g., exaggerating or downplaying the risk involved), their preferred or desired decisions, or their expected outcome or consequence of different choices.

- **Hiding**
  - Hiding was mainly used by professionals and carers and usually involved either downplaying or keeping bad news from the patient, usually in order to maintain the patients’ harmony. For example, if the patient had a major stroke, her doctor and family not decide to ‘hide’ the seriousness of her condition. They might either tell her that she only had a minor problem, or
talk about her condition outside the patient’s room or in doctors’ office rather than in front of her. As a result, the patient wasn’t in control of information all the time, and couldn't make informed decision at all.

**Negotiating**

In order to reduce the possibility of disagreement between different parties, decisions might be made through negotiation in which people discuss or talk with others in order to resolve potential disputes and achieve a mutual consensus. For example, family carers might negotiate with doctors about whether a patient could be given an examination/treatment which was less expensive or was covered by health insurance. Towards the end of their stay in hospital, patients might negotiate with doctors the possibility of getting out of bed and walking around the ward, or taking early discharge.

In addition to the above processes that revolved largely about patterns of communication other factors influencing decision-making could be divided into:

- **Medical/treatment related factors**
  - **Risk/cost** could determine who was involved in decision-making. 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 likely carers played a major role.
  - **Urgency of decision or patient’s condition**, e.g., doctors 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 patient’s condition.

- **Personal characteristics or patient/carer related factors**
  - **Level of education**: patients/carers with higher education level seemed to play a more active role in decision-making.
  - **Gender**: men (such as the husband and son-in-law) were more likely than women (such as the patient and her daughter) to use or draw on job-related knowledge (i.e., knowledge gained from their daily working experiences), and to tend to see caring or decision-making as their job.
  - **Carer’s ability to pay** would decide who played a major role in making decisions.
  - **Carer’s perceived competence to make decisions** would decide who played a major role in making decisions.
Health insurance: whether health insurance covered the cost for treatment/examination would influence the choice on that particular treatment/examination.

Economic/financial condition: carers with financial difficulties could refuse an examination/treatment due to its high cost.

Interpersonal factors
- Potential role of other patients: the positive information about a particular doctor given by other patients might enable the current patient to trust that doctor and want to see him/her for treatment.

Professional related factors
- Doctor’s experience: the role of experience in deciding which patient was most likely to benefit from treatment was very important. Doctors might tailor the information to carers depending on what they thought that the clinical outcome or the expected consequence of a particular treatment choice was likely to be.
- Perceived seniority of doctor: the older and more senior doctors were, the more patients/carers trusted them and followed their advice.
- First impression about a doctor given to patient/carer: the negative complaints about a doctor given to a new patient by a current patient could influence the nature of the relationship between the new patient and the doctor, and further influence the new patient’s decision-making.
- Staff expertise or quality of service: when deciding to go to which hospital, the carer would need to think about staff expertise or quality of service and distance between hospital and home, and was more likely to prioritise the staff expertise or quality of service over the convenience.
- Hospital reputation seemed an important consideration for carers when they decided which hospital they wanted to go to. Moreover, good reputation seemed to help carers establish the trust in the hospital.

Environmental factors
- Distance between home and hospital: patients/carers seemed to prefer to go to the hospital which was located close to patient’s home.
- Quality of physical environment seemed to be a very important consideration for patient/carer to make a choice about which hospital to go to, especially if they needed to choose among hospitals with the same levels of staff expertise or quality of service.

Please answer the following questions.
Do the processes and factors described above ‘make sense’ to you and do you recognize them from your own day to day work?

Do the processes and factors described capture the main influences on decision-making or are there any important processes and factors missing?

Could these findings be used to help patients, carers and staff to make decisions more effectively? If so, how?

Could the findings be useful in the training of doctors, nurses and other staff?

Could they be useful in producing information/advice/guidance for patients and carers?

Do you have any other comments or suggestions on the findings from the study?

Thank you very much
Appendix 28 Participants’ Feedbacks Gained During Member Checking

Member checking was carried out during which the final key findings were tested with participants in order to ensure that a good quality grounded theory was produced. The summary of the major findings were sent back to participants who were professionals by email in order to seek their knowledge and input by asking them to comment on the results of the study. They were invited to read through the brief summary and answer a couple of questions as well as give additional comments or suggestions on the findings from the study. Eleven out of 19 professionals (including 9 doctors, 1 nurse and 1 physiotherapist) to whom the summary of findings was sent back had given their feedback. Participants gave both positive and negative comments, pointed out the strength and weakness of the findings, suggested the way to overcome the weakness, and added some new information. Participants’ important feedbacks and comments are presented below and categorised according to different questions.

Do the processes and factors described ‘make sense’ to them and do they recognize them from their own day to day work?

Participants believed that an in-depth and detailed exploration of the research topic had been carried out, and a comprehensive and clear understanding had been gained. The summary was very comprehensive, accurately reflected their own experiences and perceptions, and was written from a neutral point of view rather than from the researcher’s personal perspective. The description of the main findings was very clear and easy-to-understand.

They thought that the processes and factors described were very common in their clinical practice, and they often encountered these processes, factors or situations each day when working with patients and carers, so they could easily recognise them from their own daily work.

From the findings of the study, participants found some new information or knowledge which they didn’t understand or had not yet encountered or experienced such as the role of religious beliefs in influencing decision-making processes, and thought that this new information deepened their knowledge and broadened their views.

Some of the findings gained from the in-depth explorations were considered as the areas lack of enough attention, for instance, the essential role of maintaining harmony and trust in strongly influencing decision-making activities was believed to be one of the important issues which some participants had not yet carefully thought about in this way and given a thorough consideration before, or to be a new area that was far beyond their understanding.
One participant particularly gave suggestions on how to improve the way in which the findings were presented, for example, the findings could be categorised into patient-related issues, doctor-related issues, family-related issues, and others, which she believed would make the descriptions clearer and more easy-to-understand.

**Do the processes and factors described capture the main influences on decision-making or are there any important processes and factors missing?**

Participants thought that the processes and factors described were very comprehensive and able to capture the main influences on decision-making and cover main issues in this area. In addition to capturing the whole picture of what happened in participants’ daily clinical practice, the findings presented some new knowledge or information which they didn’t know about, so most of the participants didn’t think that there were some important issues missing or there was something that needed to be added.

However, there was also new input into the findings. For example, one participant pointed out the influence of patients'/carers’ clear understanding about the health insurance policy on their decision-making. Especially since there were different policies or regulations depending on different types of diseases or different stages of the same disease, so a clear understanding on the policy or regulations would greatly help patients/carers more easily make decisions involving the issue of cost.

Another participant considered the health education delivered by health professionals as one of the important sources from which patients and carers gained knowledge. For example, in the ward of the neurological department, they often organised or delivered the health education sessions on a regular basis.

According to this participant, the topics involved were usually health care related knowledge about different types of prevalent conditions such as hypertension or stroke. The essential purposes were to increase patients'/carers’ common health related knowledge, provide guidance or instructions on healthy way of life, improve their understanding of their own diseases and treatment, and further influence or facilitate their participation in decision-making processes. This reflected a form of professionals’ sharing behaviour.

**Could these findings be used to help patients, carers and staff to make decisions more effectively? If so, how?**

Participants believed that the findings covered the major and important issues in the area of making decisions in stroke care, and could be used to help patients, carers, and professionals make decisions more effectively. On the one hand, in terms of the benefits for patients and their family members, for example, a better understanding
of the main findings could help them to know how to gain and seek more comprehensive information about patients’ condition and treatment and how to more effectively communicate with professionals, and help them make more appropriate decisions.

On the other hand, the findings could help professionals more successfully make decisions with patients and carers. For instance, the findings allowed professionals to have clearer understanding about patients’/carers’ needs, concerns, and preferences for making decisions, and provide better support to patients/carers when they need to make decisions. More importantly, participants emphasised two issues, i.e., establishing and maintaining harmony and undertaking effective communication with patients and carers. The study findings increased participants’ awareness of the important role of maintaining harmony in facilitating decision-making. For example, a participant believed that from the main findings of the study, she understood the importance of creating and maintaining harmony at different levels or dimensions, in particular establishing harmonious relationships between different groups of people or different parties in people’s decision-making practice. She pointed out that in the current health care context in China, maintain harmony was an important issue which needed to be addressed and discussed, as well as an essential purpose or goal when health professionals worked with patients/carers. However, it was also an area which had been ignored, and needed much more attention and to be improved through great efforts.

The strong influence of effective communication between professionals and patients and carers on their decision-making process was also frequently highlighted. Based on the study findings, participants understood that they needed to make more efforts to improve their communication skills when making decisions with patients/carers, and in doing so, they would be able to build and facilitate the mutual understanding with patients and carers, communicate and work with them more successfully, and establish a more harmonious relationship between each other. Meanwhile, the effective communication could help professionals provide more support to patients/carers, and allow patients/carers to have more trust in professionals and more easily, quickly and effectively make decisions. And as a result, their quality of service would be better improved.

Equally importantly, participants identified useful strategies of facilitating good interpersonal communication from the study findings, such as maintaining eye-contact with patients/carers when they communicated with patients/carers; paying attention to their feelings, reactions, and concerns; frequently and actively communicating with them; providing clear and enough information about patients’
condition and treatment interventions; respecting patients’/carers’; and providing information based on their needs. Participants expressed their willingness to apply these strategies to their day to day practice.

In order to facilitate the application of the findings to their daily work, a participant suggested that the findings could be used to develop working procedures or guidance for clinical practice. As a result, the findings could help improve professionals’ quality of service, help them successfully work with patients/carers, and help patients/carers more effectively make decisions.

Could the findings be useful in the training of doctors, nurses and other staff?
Participants thought that the findings were very useful in the training of doctors, nurses and other professionals. They suggested that it’s very important and necessary to use the findings to provide training to them, especially to students who were receiving health care related education. Other people or staff who worked in the area related to health insurance also needed to receive the training. This was considered able to help professionals and patients/carers more successfully communicate between each other and understand each other, and allow appropriate decision to be made and allow patient to have a good recovery.

One participant viewed effective communication with patients and family members as an important skill and also an area where there were lots of things to learn. He commented that in clinical practice, he noticed that only very experienced professionals could have and use very good communication skills when they worked with patients and carers in decision-making process. Therefore, communication skill or technique was one of the important issues or areas during the training process.

Another participant warned that although the findings could be useful in training professionals and other staff members, people still needed to have more practice or more experiences of making decision with patients/carers in order to have better understanding about the issues addressed in the findings.

Could they be useful in producing information/advice/guidance for patients and carers?
It was agreed that the findings were very useful in producing information, advice or guidance for patients and carers. What patients and carers had learned from the findings would enable them to know more clearly about how professionals provide treatment and health care, provide support for their decision-making, and work with them, to have better communication with professionals, to better understand each
other, and to make decisions more effectively. Besides, a participant added that providing more health related information or basic medical or clinical knowledge to patients and carers were equally important in their decision-making. Another participant suggested that the description of findings could be made simpler and clearer by presenting them in point form.

Do they have any other comments or suggestions on the findings from the study?
Some participants gave no additional comments or suggestions on the findings, and considered them to be very comprehensive and able to facilitate patients’ and carers’ participation in decision-making. While some participants expressed different opinions, added new suggestions, or gave additional comments about the weakness of the findings. For example, several participants held different opinions on the role of information exchanging behaviour between patients and carers sharing the same ward in their making decisions. One participant indicated that the exchanging process might not necessarily be able to facilitate the establishment and maintenance of the harmonious relationship between patients/carers and professionals. He thought that since patients/carers didn't have enough medical knowledge, so they might not be able to have correct understanding about patients’ disease condition and treatment. Therefore, when different patients demonstrated the similar clinical manifestation, they might feel that these patients suffered from the same condition. But actually that might not be the case, those patients might actually have different conditions, should be given different treatment, and obviously would have different prognosis. So according to this participant, when they watched and compared the condition and treatment of different patients, they might come up with some misunderstandings and couldn't understand the different interventions given to the different patients with the seemingly similar condition, then as a result, they might not be able to establish trust in their doctors or nurses. So the exchanging process between patients/carers sharing the same ward might potentially lead to their distrust in doctors and nurses. Another participant had the similar perspective about the impact of exchanging process on decision-making. She thought that when making decisions, patients and carers should mainly and often follow doctors’ advice, because generally speaking, doctors were able to give the best possible advice based on their own professional knowledge and clinical experiences. However, sometimes, the discussions between patients and their family members,
or discussions between fellow patients and their carers were only based on their own limited knowledge and information, so these discussions or communications might lead to wrong decisions.

Interestingly, one participant highlighted the continuous nature of the decision-making process. To him, decision-making was a process through which doctors, patients and carers closely and continually worked together to make decisions. For example, they made decisions, then managed things that happened after decision was made, or namely, dealt with the outcome or results of their decision, and then again further made decision on the next step to take. So decision-making was considered by him as an ongoing process throughout which three parties continually made efforts in order to solve patients’ health problems.

Several participants gave further recommendations. For instance, a participant suggested that the findings should be published as quickly as possible, and this could allow more patients, family carers and professionals to benefit from the findings, and help them more harmoniously work together and more easily make correct and effective decisions. Another participant hoped that the findings could be applied to clinical practice through a way in which the researchers developed a working procedure or protocol based on the findings in order to guide the decision-making practice.

A participant gave negative comments on the summary of study findings, and pointed out the weakness in its organisation or presentation which was considered poor-organised, especially given a large amount of information involved. She further advised that since the main findings involved many important issues, so further efforts needed to be made to make the presentation clearer and better-organised.