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

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References

Abegunde, D. O., Mathers, C. D., Adam, T., Ortegon, M. and Strong, K. (2007) The burden and costs of chronic diseases in low-income and middle-income countries. *Lancet,* 370, 1929–1938.

Alaszewski, H., King, A., Alaszewski, A. and Potter, J. (2008) Communicating information to stroke survivors: a pilot study [online]. Kent, Centre for Health Services Studies, University of Kent. Available from: http://www.kent.ac.uk/chss/researchcentre/docs/communicating_information.pdf [Accessed 30th December 2009]

Almborg, A. H., Ulander, K., Thulin, A. and Berg, S. (2008) Patients' perceptions of their participation in discharge planning after acute stroke. *Journal of Clinical Nursing,* 18, 199-209.

American Nurses Association. (2010) Standards of professional nursing practice [online]. Washington, DC, American Nurses Association. Available from: http://library.brcn.edu/upload/docs/BRCN/Library/ANA/eBk_SL%20Nursing%20Scope%20%20Standards%202e%202010.pdf [Accessed 1st January 2013].

Andersson, A. and Hansebo, G. (2009) Elderly peoples' experience of nursing care after a stroke: from a gender perspective. *Journal of Advanced Nursing,* 65(10), 2038–2045.

Andrews, T. and Nathaniel, A. K. (2009) Awareness of dying revisited. *Journal of Nursing Care Quality,* 24(3), 189–193.

Annells, M. (1996) Grounded theory method: philosophical perspectives, paradigm of inquiry, and postmodernism. *Qualitative Health Research,* 6(3), 379-393.

Arora, N. K. and McHorney, C. A. (2000) Patient preferences for medical decision making: who really wants to participate? *Medical Care,* 38(3), 335-341.

Bartlett, D. and Payne, S. (1997) Grounded theory – its basis, rationale and procedures. In: G, McKenzie, J, Powell and R, Usher (eds) *Understanding social research: perspectives on methodology and practice.* London, Falmer. pp. 173-195.

Becker, Howard S. (1986) *Doing things together.* Evanston, Northwestern University Press.

Belcher, V. N., Fried, T. R., Agostini, J. A. and Tinetti, M. E. (2006) Views of older adults on patient participation in medication-related decision making. *Journal of General Internal Medicine,* 21, 298–303.

Benner, Patricia, Tanner, Christine A. and Chesla, Catherine A. (1996) *Expertise in nursing practice: caring, clinical judgement and ethics.* New York, Springer.

Benoliel, J. (1984) Advancing nursing science: qualitative approaches. *Western Journal of Nursing Research,* 6(3), 1-8.

Benoliel, J. (1996) Grounded theory and nursing knowledge. *Qualitative Health Research,* 6(3), 406-428.

Benson, J. and Britten, N. (1996) Respecting the autonomy of cancer patients when talking with their families: qualitative analysis of semi-structured interviews with patients. *British Medical Journal,* 313, 729–731.

Berg, Bruce L. (2007) *Qualitative research methods for the social sciences.* 6th edition. Boston, Pearson/Allyn & Bacon.

Berger, J. T. (1998) Culture and ethnicity in clinical care. *Archives of Internal Medicine*, 158, 2085–2090.

Biley, F. C. (1992) Some determinants that effect patient participation in decision-making about nursing care. *Journal of Advanced Nursing,* 17, 414-421.

Bishop, D. (1980) Behavior and disability: challenges for assessment and management. In: D, S, Bishop (ed) *Behavioral problems and disabled.* Baltimore, Williams & Wilkins Co. pp. 1-16.

Blackhall, L. J., Murphy, S. T., Frank, G., Michel, V. and Azen, S. (1995) Ethnicity and attitudes toward patient autonomy. *Journal of the American Medical Association,* 274, 820–825.

Blanck, A. W. and Marshall, C. (2011) Patient education materials from the layperson's perspective: the importance of readability. *Journal for Nurses in Staff Development,* 27(2), E8-E10.

Bogardus, Jr. S. T., Bradley, E. H., Williams, C. S., Maciejewski, P. K., Doorn, C. V. and Inouye, S. K. (2001) Goals for the care of frail older adults: do caregivers and clinicians agree? *The American Journal of Medicine,* 110, 97-102.

Bogdan, Robert C. and Biklen, Sari K. (1982) *Qualitative research for education: an introduction to theories and methods*. Boston, Allyn and Bacon.

Bosworth, H. B., Stechuchak, K. M., Grambow, S. C. and Oddone, E. Z. (2004) Patient risk perceptions for carotid endarterectomy: which patients are strongly averse to surgery? *Journal of Vascular Surgery,* 40(1), 86-91.

Bowman, K. W. and Singer, P. A. (2001) Chinese seniors’ perspectives on end-of-life decisions. *Social Science & Medicine,* 53, 455-464.

Brereton, L. and Nolan, M. (2002) ‘Seeking’: a key activity for new family carers of stroke survivors. *Journal of Clinical Nursing,* 11, 22-31.

Brereton, L. and Nolan, M. (2003) Seeking partnerships between family and professional carers: stroke as a case in point. In: M, Nolan, U, Lundh, G, Grant and J, Keady (eds) *Partnerships in family care: understanding the caregiving career.* Maidenhead, Open University Press. pp. 50-68.

Brown, J., Nolan, M. and Davies, S. (2001) Who’s the expert?: redefining lay and professional relationships. In: M, Nolan, S, Davies and G, Grant (eds) *Working with Older People and Their Families: Key Issues in Policy and Practice.* Buckingham, Open University Press. pp 19-32.

Brown, P. H. and Theoharides, C. (2009) Health-seeking behaviour and hospital choice in China’s new cooperative medical system. *Health Economics,* 18, S47–S64.

Brown Wilson, C. and Clissett, P. (2011) Involving older people in research: practical considerations when using the authenticity criteria in constructivist inquiry. *Journal of Advanced Nursing,* 67(3), 677–686.

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

(Office Edition), 30(2), 43-46, 49-52, 111-113.

Carlander, I., Ternestedt, B., Sahlberg-Blom, E., Hellström, I. and Sandberg, J. (2011) Being me and being us in a family living close to death at home. *Qualitative Health Research,* 21(5), 683–695.

Casey, D. (2006) Choosing an appropriate method of data collection. *Nurse Researcher,* 13(3), 75-92.

Chang, K. C., Tseng, M. C. and Tan, T. Y. (2004) Prehospital delay after acute stroke in Kaohsiung Taiwan. *Stroke,* 35, 700-704.

Chang, S. J., Lee, K. J., Kim, I. S. and Lee, W. H. (2008) Older Korean people's desire to participate in health care decision making. *Nursing Ethics,* 15(1), 73-86.

Chang, Y. P. and Schneider, J. K. (2010) Decision-making process of nursing home placement among Chinese family caregivers. *Perspectives in Psychiatric Care,* 46(2), 108-118.

Charles, C., Gafni, A. and Whelan, T. (1997) Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science and Medicine,* 44(5), 681-692.

Charles, C., Whelan, T. and Gafni, A. (1999a) What do we mean by partnership in making decisions about treatment? *BMJ,* 319, 780–782.

Charles, C., Gafni, A. and Whelan, T. (1999b) Decision making in the physician-patient encounter: revisiting the shared treatment decision making model. *Social Science & Medicine,* 49, 651-661.

Charmaz, K. (2000) Grounded theory: objectivist and constructivist methods. In: N, K, Denzin and Y, S, Lincoln (eds) *Handbook of qualitative research.* 2nd edition. Thousand Oaks, SAGE. pp. 509–535.

Charmaz, Kathy (2006) *Constructing grounded theory: a practical guide through qualitative analysis.* London, Sage Publications Ltd.

Charmaz, K. and Mitchell, R. G. (2001) An invitation to grounded theory in ethnography. In: P, Atkinson, A, Coffey, S, Delamonte, J, Lofland and L, H, Lofland (eds) *Handbook of ethnography.* London, Sage. pp. 160-174.

Chen, G. M. (2002) The impact of harmony on Chinese conflict management. In: G, M, Chen and R, Ma (eds) *Chinese conflict management and resolution.* Westport, Greenwood Publishing. pp. 3-19.

Chen, G. M. and Starosta, W. J. (1997) Chinese conflict management and resolution: overview and implications. *Intercultural Communication Studies*, 7, 1-16.

Chen, H. H. (1987) Integrating ancient and modern medicine in Chinese hospitals: the interaction among technology, traditional Chinese medicine, and health care. *International Journal of Technology Assessment in Health Care,* 3, 265-274.

Chen, K. J. and Xu, H. (2003) The integration of traditional Chinese medicine and Western medicine. *European Review,* 11(2), 225–235.

Chen, T. (2004) Pricing private health insurance products in China [online]. Available from: http://www.actuaries.org/IAAHS/Colloquia/Dresden/Tao%20paper.pdf
[Accessed 16th January 2011]

Chen, X. Y. and Fan, R. P. (2010) The family and harmonious medical decision making: cherishing an appropriate Confucian moral balance. *Journal of Medicine and Philosophy,* 35, 573–586.

Chenitz, W. C. (1986) Getting started: the research proposal for a grounded theory study. In: W, C, Chenitz and J, M, Swanson (eds) *From practice to grounded theory.* Menlo Park, Addison-Wesley. pp. 39-47.

Chinese Medical Association's Neuropathy Branch for Cerebrovascular Disease Study Group (2010) Chinese guideline for diagnosis and management of acute ischemic stroke. *Chinese Journal of Neurology*, 43, 146–153.

Christensen, J. M. and Anderson, J. D. (1989) Spouse adjustment to stroke: aphasic versus nonaphasic partners. *Journal of communication disorders,* 22, 225-231.

City Express. (2010) Tianjin: one of the top cities of ageing population [online]. Tianjin, City Express, Tuesday August 17 2010, p.1. Available from:
http://www.chinadaily.com.cn/dfpd/tianjin/2010-08-17/content_718018.html
[Accessed 16th January 2011]

Cong, Y. L. (2004) Doctor-family-patient relationship: the Chinese paradigm of informed consent? *Journal of Medicine and Philosophy,* 29(2), 149-178.

Corbin, J. (1986) Coding, writing memos, and diagramming. In: W, C, Chenitz and J, M, Swanson (eds) *From practice to grounded theory: qualitative research in nursing.* Menlo Park, Addison-Wesley. pp. 102-120.

Coulter, A. (1999) Paternalism or partnership? Patients have grown up—and there's no going back. *BMJ,* 319, 719–20.

Courtney R., Ballard E., Fauver S., Gariota M. and Holland L. (1996) The partnership model: working with individuals, families, and communities toward a new vision of health. *Public Health Nursing,* 13, 177–186.

Cox, E. O., Dooley, A., Liston, M. and Miller, M. (1998) Coping with stroke: perceptions of elderly who have experienced stroke and rehabilitation interventions. *Topics in Stroke Rehabilitation,* 4, 76-88.

Davies, S. (2001) *Wanting what's best for them: relatives' experiences of nursing home entry: a constructivist inquiry.* PhD thesis, University of Sheffield.

Davies, S., Atkinson, L., Aveyard, B., Martin, U., McCaffrey, S. and Powell, A. (2007) Changing the culture within care homes for older people. In M, Nolan, E, Hanson, G, Grant and J, Keady (eds) *User participation in health and social care research - voices, values and evaluation.* Maidenhead, Open University Press. pp. 50-68.

Davies, S. and Nolan, M. (2003) 'Making the best of things': relatives' experiences of decisions about care-home entry. *Ageing & Society,* 23, 429–450.

Deber, R. B., Kraetschmer, N., Urowitz, S. and Sharpe, N. (2007) Do people want to be autonomous patients: preferred roles in treatment decision-making in several patient populations. *Health Expectations,* 10, 248–258.

Denzin, Norman K. (1989) *The research act: a theoretical introduction to sociological methods.* Englewood Cliffs, Prentice Hall.

Denzin, N. K. and Lincoln, Y. S. (2005) Introduction: the discipline and practice of qualitative research. In: N, K, Denzin and Y, S, Lincoln (eds) *The SAGE book of qualitative research.* 3rd edition. Thousand Oaks, Sage Publications. pp. 1-32.

Department of Health. (2001a) The expert patient: a new approach to chronic disease management in the 21st century [online]. London, Department of Health. Available from:
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4018578.pdf [Accessed 6th May 2013]

Department of Health. (2001b) National service framework for older people [online]. London, Department of Health. Available from:
http://www.rcgp.org.uk/pdf/ISS_SUMM01_02.pdf [Accessed 26th April 2010]

Dewar, B. (2007) Promoting positive culture in care homes. In: My home life: quality of life in care homes, a review of the literature [online]. London, Help the Aged. Available from: http://www.myhomelife.org.uk/resources/mhl.review.pdf [Accessed 5th January 2013].

Dumoulin-Smith, A. (2008) Social health insurance in China: an example of nascent social security in China [online]. Available from:
http://inequality.cornell.edu/people/PapersAbstracts/Dumoulin%20Smith_paper.pdf [Accessed 16th January 2011]

Eames, S., Hoffmann, T., Worrall, L. and Read, S. (2010) Stroke patients' and carers' perception of barriers to accessing stroke information. *Topics in Stroke Rehabilitation,* 17(2), 69-78.

Eaves, Y. D. (2000) 'What happened to me': rural African American elders' experiences of stroke. *Journal of Neuroscience Nursing,* 32, 37-48.

Efraimsson, E., Sandman, P. O., Hydén, L. C. and Rasmussen, B. H. (2004) Discharge planning: "fooling ourselves?"-patient participation in conferences.

Journal of Clinical Nursing, 13(5), 562-570.

Eggleston, K., Shen, Y., Lau, J., Schmid, C. H. and Chan, J. (2008) Hospital ownership and quality of care: what explains the different results in the literature? *Health Economics,* 17(12), 1345–1362.

Ellis-Hill, C., Payne, S. and Ward, C. (2000) Self-body split: issues of identity in physical recovery after stroke. *Disability and Rehabilitation,* 22, 725-733.

Elwyn, G., Edwards, A., Gwyn, R. and Grol, R. (1999) Towards a feasible model for shared decision making: focus group study with general practice registrars. *BMJ,* 319, 753–756.

Elwyn, T. S., Fettersb, M. D., Sasakic, H. and Tsudad, T. (2002) Responsibility and cancer disclosure in Japan. *Social Science & Medicine,* 54, 281–293.

Entwistle, V. (2004) Trust and shared decision-making: an emerging research agenda. *Health Expectations,* 7, 271–273.

Epstein, R. M., Alper, B. S. and Quill, T. E. (2004) Communicating evidence for participatory decision making. *JAMA,* 291(19), 2359-2366.

Erlandson, David A., Harris, Edward L., Skipper, Barbara L. and Allen, Steve D. (1993) *Doing naturalistic inquiry: a guide to methods.* Newbury Park, Sage Publications Inc.

Evans, R. L., Connis, D. S., Bishop, D. S., Hendricks, R. D. and Haselkorn, J. K. (1994) Stroke: a family dilemma. *Disability and Rehabilitation,* 16(3), 110-118.

Fan, Ruiping. (2010) *Reconstructionist Confucianism: rethinking morality after the West.* New York, Springer.

Fan, Y. (2000) A classification of Chinese culture. *Cross Culture Management,* 7(2), 3-10.

Florin, J., Ehrenberg, A. and Ehlfors, M. (2006) Patient participation in clinical decision-making in nursing: a comparative study of nurses' and patients' perceptions. *Journal of Clinical Nursing,* 15(12), 1498-1508.

Fox, J. (2003) Consumerism 1: the different perspectives within health care. *British Journal of Nursing*, 12(5), 321–326.

Fox, N. (1998) Trent focus for research and development in primary health care: how to use observations in a research project [online]. Available from: http://web.simmons.edu/~tang2/courses/CUAcourses/lsc745/sp05/observation.pdf [Accessed 27th February 2012]

Fraenkel, L. and McGraw, S. (2007a) Participation in medical decision making: the patients' perspective. *Medical Decision Making,* 27, 533-538.

Fraenkel, L. and McGraw, S. (2007b) What are the essential elements to enable patient participation in medical decision making? *Journal of General Internal Medicine*, 22, 614–619.

Gallant, M. H., Beaulieu, M. C. and Carnevale, F. A. (2002) Partnership: an analysis of the concept within the nurse–client relationship. *Journal of Advanced Nursing,* 40 (2), 149–157.

Ganz, F. D., Benbenishty, J., Hersch, M., Fischer, A., Gurman, G. and Sprung, C. L. (2006) The impact of regional culture on intensive care end of life decision making: an Israeli perspective from the ETHICUS study. *Journal of Medical Ethics,* 32, 196–199.

Geertz, C. (1973) Thick description: towards an interpretive theory of culture. In: C, Geertz (ed) *The interpretation of cultures: selected essays.* New York, Basic Books. pp. 3-32.

Gibson, J. (2002) Use of qualitative research to analyze patient and clinician decision making in carotid endarterectomy. *Journal of Vascular Nursing,* 20, 60-65.

Glaser, Barney G. (1978) *Theoretical sensitivity.* Mill Valley, Sociology Press.

Glaser, Barney G. (1998) *Doing grounded theory: issues and discussions.* Mill Valley, Sociology Press.

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

Glaser, Barney G. and Strauss, Anselm L. (1967) *The discovery of grounded theory: strategies for qualitative research.* New York, Aldine.

Gold, R. L. (1958) Roles in sociological field observations. *Social Forces,* 36, 217-223.

Guba, Egon G. and Lincoln, Yvonna S. (1989) *Fourth generation evaluation.* Newbury Park, Sage.

Guba, E. G. and Lincoln, Y. S. (1994) Competing paradigms in qualitative research. In: N, K, Denzin and Y, S, Lincoln (eds) *Handbook of qualitative research.* Thousand Oaks, Sage. pp. 105-117.

Hafsteinsdo´ttir, T. B., Vergunst, M., Lindeman, E. and Schuurmans, M. (2011) Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. *Patient Education and Counseling,* 85, 14-25.

Hallstro¨m, I and Elander, G. (2004) Decision-making during hospitalization: parents’ and children’s involvement. *Journal of Clinical Nursing,* 13, 367–375.

Hanger, H. C., Walker, G., Paterson, L. A., McBride, S. and Sainsbury, R. (1998) What do patients and their carers want to know about stroke? A two-year follow-up study. *Clinical Rehabilitation,* 12, 45–52.

Hanson, E., Magnusson, L., Nolan, J. and Nolan, M. R. (2006) Developing a model of participatory research involving researchers, practitioners, older people and their family carers. *Journal of Research in Nursing,* 11(4), 325–342.

Hasselkus, B. R. (1992) Physician and family caregiver in the medical setting: negotiation of care? *Journal of Aging Studies,* 6(1), 67-80.

Hattori, A., Masuda, Y., Fetters, M. D., Uemura, K., Mogi, N., Kuzuya, M. and Iguchi, A. (2005) A qualitative exploration of elderly patients' preferences for end-of-life care. *Japan Medical Association Journal,* 48(8), 388-397.

Haug, M. R. (1994) Elderly patients, caregivers and physicians: theory and research on health care triads. *Journal of Health and Social Behaviour,* 35, 1-12.

Health Care Commission. (2005) Survey of patients: stroke [online]. London, Commission for Healthcare Audit and Inspection. Available from:
http://www.rsucardiff.org.uk/resource/HC.StrokePatientSurvery.2005.pdf
[Accessed 16th January 2010]

Health Care Commission. (2006) Survey of patients: caring for people after they have had a stroke - a follow-up survey of patients [online]. London, Commission for Healthcare Audit and Inspection. Available from:
http://qualityimprovementscotland.net/nhsqis/files/stroke_survey_update.pdf
[Accessed 16th January 2010]

Hedberg, B., Johanson, M. and Cederborg, A. C. (2008) Communicating stroke survivors' health and further needs for support in care-planning meetings. *Journal of Clinical Nursing,* 17, 1481-1491.

Heeley, E., Anderson, C. S., Huang, Y., Jan, S., Li, Y., Liu, M., Sun, J., Xu, E., Wu, Y., Yang, Q., Zhang, J., Zhang, S. and Wang, J. (2009) Role of health insurance in averting economic hardship in families after acute stroke in China. *Stroke,* 40, 2149-2156.

Hellström, I., Nolan, M. and Lundh, U. (2005) Awareness context theory and the dynamics of dementia: improving understanding using emergent fit. *Dementia*, 4(2), 269–295.

Henderson, A. and Shum, D. (2003) Decision-making preferences towards surgical intervention in a Hong Kong Chinese population. *International Nursing Review*, 50, 95-100.

Higgins, I. (1998) Pearls, pith and provocation: reflections on conducting qualitative research with elderly people. *Qualitative Health Research,* 8(6), 858-866.

Hilton, E. (2002) The meaning of stroke in elderly women: a phenomenological investigation. *Journal of Gerontological Nursing,* 28, 19-26.

Hinds, P. S., Chaves, D. E. and Cypess, S. M. (1992) Context as a source of meaning and understanding. *Qualitative Health Research*, 2(1), 61-74.

Hjelmblink, F. (2008) *Understanding life after stroke.* PhD Thesis, Uppsala University.

Hoffmann, T. and Cochrane, T. (2009) What education do stroke patients receive in Australian hospitals? *Patient Education and Counseling*, 77, 187–191.

Hook, M. L. (2006) Partnering with patients – a concept ready for action. *Journal of Advanced Nursing*, 56(2), 133–143.

Hornung, C. A., Eleazer, G. P., Strothers, H. S., Wieland, G. D., Eng, C., McCann, R. and Sapir, M. (1998) Ethnicity and decision-makers in a group of frail older people. *Journal of the American Geriatrics Society,* 46, 280–286.

Hoshino, K. (1995) Autonomous decision making and Japanese tradition. *Cambridge Quarterly of Healthcare Ethics*, 4, 71–74.

Hougaard, J. L. Østerdal, L. P. and Yu, Y. (2011) The Chinese healthcare system: structure, problems and challenges. *Applied Health Economics and Health Policy,* 9 (1), 1-13.

Huang, H. X. (2005) Some thoughts on establishment of medical care insurance for older people. *Health Economics Research,* 9, 22-23.

Huang, Z. B., Neufeld, R. R. Likourezos, A., Breuer, B., Khaski, A., Milano, E. and Libow, L. S. (2003) Socio-demographic and health characteristics of older Chinese on admission to a nursing home: a cross-racial/ethnic study. *Journal of the American Geriatrics Society,* 51(3), 404–409.

Hubbard, G., Illingworth, N., Rowa-Dewar, N., Forbat, L. and Kearney, N. (2010) Treatment decision-making in cancer care: the role of the carer. *Journal of Clinical Nursing,* 19, 2023–2031.

Huby, G., Brook, J. H., Thompson, A. and Tierney, A. (2007) Capturing the concealed: interprofessional practice and older patients' participation in decision making about discharge after acute hospitalization. *Journal of Interprofessional Care*, 21(1), 55-67.

Humayun, A., Fatima, N., Naqqash, S., Hussain, S., Rasheed, A., Imtiaz, H. and Imam, S. Z. (2008) Patients' perception and actual practice of informed consent, privacy and confidentiality in general medical outpatient departments of two tertiary care hospitals of Lahore. *BMC Medical Ethics*, 9, 14.

Hutchinson, S. A., Leger-Krall, S. and Wilson, H. S. (1997) Early probable Alzheimer’s disease and awareness context theory. *Social Science and Medicine,* 45 (9), 1399–1409.

Ip, M., Gilligan, T., Koenig, B. and Raffin, T. A. (1998) Ethical decision-making in critical care in Hong Kong. *Critical Care Medicine*, 26, 447-451.

Jewell, S. (1996) Elderly patients participation in discharge decision making: 1. *British Journal of Nursing,* 5(15), 914–922.

Jia, G. T. (2004) Issues about medical care in ageing society. *Foreign Medicine (Social Medicine),* 21(1), 45-46.

Jiang, L. L., Chao, J. Q., Liu, H., Xie, W. Y. and Tian, L. (2010) The analysis of status and influencing factors of medical insurance among urban older population. *Modern Preventive Medicine,* 37(20), 3860-3864.

Jun, G., Raven, J. H. and Tang, S. L. (2007) Hospitalisation among the elderly in urban China. *Health Policy,* 84, 210–219.

Kagawa-Singer, M. (1996) Issues affecting Asian American and Pacific American women. In: K, H, Dow (ed) *Contemporary issues in breast cancer.* Boston, Jones and Bartlett. pp. 229-241.

Kahraman, A. and Jones, F. (2009) Factors influencing and shaping the lived experience after stroke: a systematic review of qualitative studies [online]. Adelaide, The Joanna Briggs Institute. Available from: http://www.joannabriggs.edu.au/protocols/Protocol237.pdf [Accessed 27th November 2009].

Kao, H. F. and Stuifbergen, A. K. (1999) Family experiences related to the decision to institutionalize an elderly member in Taiwan: an exploratory study. *Social Science & Medicine,* 49, 1115-1123.

Kapral, M. K., Devon, J., Winter, A., Wang, J., Peters, A. and Bondy, S. J. (2006) Gender differences in stroke care decision making. *Medical Care*, 44(1), 70-80.

Kelly-Powell, M. L. (1997) Personalizing choices: patients' experiences with making treatment decisions. *Research in Nursing & Health*, 20, 219–227.

Kerr, J., Hilari, K. and Litosseliti, L. (2010) Information needs after stroke: what to include and how to structure it on a website. a qualitative study using focus groups and card sorting. *Aphasiology,* 24(10), 1170–1196.

Knight, M. and Field, D. (1981) A silent conspiracy: coping with dying cancer patients on an acute surgical ward. *Journal of Advanced Nursing,* 6, 221-229.

Krefting, L. (1991) Rigor in qualitative research: the assessment of trustworthiness. *American Journal of Occupational Therapy,* 45, 214-222.

Kvale, Steinar. (1996) *Interviews: an introduction to qualitative research interviewing.* Thousand Oaks, Sage Publications.

Lam, W., Fielding, R., Chan, M., Chow, L. and Ho, E. (2003) Participation and satisfaction with surgical treatment decision-making in breast cancer among Chinese women. *Breast Cancer Research and Treatment,* 80, 171–180.

Larsson, I. E., Sahlsten, M. J. M., Sjo¨stro¨m, B., Lindencrona, C. S. C. and Plos, K. A. E. (2007) Patient participation in nursing care from a patient perspective: a grounded theory study. *Scandinavian Journal of Caring Sciences,* 21, 313–320.

Lee, D. S. (2001) Accompany the sick: a unique practice in Chinese hospitals by patients' relatives and friends. *Contemporary Nurse,* 10(3-4), 136-141.

Lee, E. (1991) Mourning rituals in Chinese culture. In: F, Walsh and M, McGoldrick (eds) *Living beyond loss: death in the family*. New York, WW Norton. pp. 201–206.

Leininger, M. (1994) Evaluation criteria and critique of qualitative research studies. In: J, M, Morse (ed) *Critical issues in qualitative research methods.* Thousand Oaks, Sage. pp. 95-115.

Leininger, Madeleine. and McFarland, Marilyn. (2002) *Transcultural nursing: concepts, theories, research, and practice.* 3rd edition. New York, McGraw-Hill.

Lennart, B., Dong, H. J., Wang, K. L., Cai, W. W. and Vinod, D. (1996) The cost of coverage: rural health insurance in China. *Health Policy and Planning,* 11(3), 238-252.

Levinson, W., Kao, A., Kuby, A. and Thisted, R. A. (2005) Not all patients want to participate in decision making: a national study of public preferences. *Journal of General Internal Medicine,* 20, 531-535.

Li, C. (2008) The philosophy of harmony in classical Confucianism. *Philosophy Compass,* 3(3), 423–435.

Li, S. J. (2005) *A community-based and family-centred care approach for stroke survivors in Wuhan city of China* [online]. PhD thesis, Hong Kong Polytechnic University. Available from: http://repository.lib.polyu.edu.hk/jspui/handle/10397/2302 [Accessed 23rd March 2012]

Liang, H. F. (2002) Understanding culture care practices of caregivers of children with cancer in Taiwan. *Journal of Pediatric Oncology Nursing,* 19(6), 205-217.

Liaschenko, J. (1997) Knowing the patient. In: S, E, Thorne and V, E, Hays (eds) *Nursing praxis: knowledge and action*. Thousand Oaks, Sage. pp. 23-38.

Liaschenko, J. and Fisher, A. (1999) Theorising the knowledge that nurses use in the conduct of their work. *Scholarly Inquiry for Nursing Practice, An International Journal,* 13(1), 29-41.

Lincoln, Y. S. (2001) Engaging sympathies: relationships between action research and social constructivism. In: P, Reason and H, Bradbury (eds) *Handbook of action research: participative inquiry and practice.* London, Sage Publications. pp. 124-132.

Lincoln, Yvonna S. and Guba, Egon G. (1985) *Naturalistic inquiry.* Beverly Hills, Sage Publications Ltd.

Liu, M. (2006) Acupuncture for stroke in China: needing more high quality evidence. *International Journal of Stroke,* 1, 34–35.

Liu, M., Wu, B., Wang, W. Z., Lee, L. M., Zhang, S. H. and Kong, L. Z. (2007) Stroke in China: epidemiology, prevention, and management strategies. *The Lancet Neurology,* 6, 456-464.

Liu, P. and Zheng, Z. Q. (2009) Analysis of the problems of health insurance system for urban older people in China and the strategies. *Chinese Primary Health Care,* 23 (7), 13-14.

Liu, X. and Hsiao, W. (1995) The cost escalation of social health insurance plans in China: its implication for public policy. *Social Science & Medicine,* 41(8), 1095-1101.

Liu, Y., Hu S., Fu, W. and Hsiao, W. C. (1996) Is community financing necessary and feasible for rural China? *Health Policy,* 38, 155–71.

Liu, Y. L. (2002) Reforming China’s urban health insurance system. *Health Policy,* 60, 133-150.

Liu, Y. L. (2004) Development of the rural health insurance system in China. *Health Policy and Planning,* 19(3), 159–165.

Long, T. and Johnson, M. (eds.) (2007) *Research ethics in the real world: issues and solutions for health and social care.* London, Churchill Livingstone, Elsevier.

Lown, B. A., Hanson, J. L. and Clark W. D. (2009) Mutual influence in shared decision making: a collaborative study of patients and physicians. *Health Expectations,* 12, 160–174.

Lundh, U., Sandberg, J. and Nolan, M. (2000) `I don't have any other choice': spouses' experiences of placing a partner in a care home for older people in Sweden. *Journal of Advanced Nursing,* 32(5), 1178-1186.

Mackenzie, A., Perry, L., Lockhart, E., Cottee, M., Cloud, G. and Mann, H. (2007) Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring. *Disability and Rehabilitation*, 29(2), 111-121.

Mangset, M., Dahl, T. E., Forde, R. and Wyller, T. B. (2008) ‘We’re just sick people, nothing else’: factors contributing to elderly stroke patients’ satisfaction with rehabilitation. *Clinical Rehabilitation,* 22, 825-835

Mansell, D., Poses, R. M., Kazis, L. and Duefield, C. A. (2000) Clinical factors that influence patients’ desire for participation in decisions about illness. *Archives of Internal Medicine*, 160, 2991-2996.

Marques, S., Rodrigues, R. A. P. and Kusumota, L. (2006) Cerebrovascular accident in the aged: changes in family relations. *Rev Latino-am Enfermagem maio-junho,* 14 (3), 364-371.

Martins, J. C. A. (2009) Patient's satisfaction with information on disease and morbidity. *Rev Latino-am Enfermagem, maio-junho,* 17(3), 335-340.

Marwit, S. J. and Datson, S. L. (2002) Disclosure preferences about terminal illness: an examination of decision-related factors. *Death Studies,* 26, 1–20.

Matteson, P. and Hawkins, J. W. (1990) Concept analysis of decision making. *Nursing Forum*, 25 (2), 4-10.

McGilton, K. S., O’Brien-Pallas, L. L., Darlington, G., Evans, M., Wynn, F. and Pringle, D. M. (2003) Effects of a relationship-enhancing program of care outcomes. *Journal of Nursing Scholarship*, 35(2), 151-156.

McKevitt, C., Redfern, J., Mold, F. and Wolfe, C. (2004) Qualitative studies of stroke: a systematic review. *Stroke,* 35, 1499-1505.

McLaughlin, L. and Braun, K. (1998) Asian and Pacific Islander cultural values: considerations for health care decision making. *Health and Social Work,* 23(2), 116-126.

Menne, H. L. and Whitlatch, C. J. (2007) Decision-making involvement of individuals with dementia. *The Gerontologist,* 47(6), 810–819.

Ministry of Health. (2009) Chinese health statistical digest 2009 [online]. Beijing, Ministry of Health. Available from: http://xn--rlr479ey7s.cn/sofpro/cms/previewjspfile/zwgkzt/cms_0000000000000000131_tpl.jsp?requestCode=40765&CategoryID=7413 [Accessed 28th November 2009]

Ministry of Health. (2010) Chinese statistical yearbook on health care 2010 [online]. Beijing, Ministry of Health. Available from: http://xn--rlr479ey7s.cn/htmlfiles/zwgkzt/ptjnj/year2010/index2010.html [Accessed 4th May 2013]

Moloczij, M., McPherson, K. M., Smith, J. F. and Kayes, N. M. (2008) Help-seeking at the time of stroke: stroke survivors' perspectives on their decisions. *Health and Social Care in the Community,* 16(5), 501–510.

Morse, J. M. (1994) Emerging from data: the cognitive processes of analysis in qualitative inquiry. In J. M. Morse (ed) *Critical issues in qualitative research methods.* Thousand Oaks, Sage. pp. 23-43.

Morse, J. M. (1998a) Validity by committee. *Qualitative Health Research,* 8(4), 443-445.

Morse, J. M. (1998b) Designing funded qualitative research. In: N, K, Denzin and Y, S, Lincoln (eds) *Strategies of qualitative inquiry.* Thousand Oaks, SAGE Publications. pp. 56-85.

Morse, J. M. (2000) Determining sample size. *Qualitative Health Research,* 10(1), 3-5.

Morse, Janice M. and Richards, Lyn. (2002) *Read me first for a user's guide to qualitative methods.* Thousand Oaks, Sage Publications.

Mulhalla, A. (2003) In the field: notes on observation in qualitative research. *Journal of Advanced Nursing,* 41(3), 306–313.

Mull, D. S., Nguyen, N. and Mull, J. D. (2001) Vietnamese diabetic patients and their physicians: what ethnography can teach us. *Western Journal of Medicine,* 175, 307–311.

Mullen, P. D. (1986) Generating grounded theory. *International Quarterly of Community Health Education,* 6(3), 177-214.

Munhall, Patricia L. (2007) *Nursing Research: a qualitative perspective.* 4th edition. Sudbury, Mass, Jones and Bartlett.

National Institute for Health and Clinical Excellence. (2008) Stroke: national clinical guideline for diagnosis and initial management of acute stroke and transient ischaemic attack (TIA) [online]. London, NICE. Available from: http://www.nice.org.uk/CG68 [Accessed 27th November 2009].

Naylor, C. D. (1999) Health care in Canada: incrementalism under fiscal duress. *Health Affairs,* 18(3), 9–26.

Ngo-Metzger, Q., Legedza, A. T. R. and Phillips, R. S. (2004) Asian Americans' reports of their health care experiences: results of a national survey. *Journal of General Internal Medicine,* 19, 111-119.

Nolan, M. and Dellasega, C. (2000) `I really feel I've let him down': supporting family carers during long-term care placement for elders. *Journal of Advanced Nursing,* 31(4), 759-767.

Nolan, M., Keady, J., Grant, G. and Lundh, U. (2003a) Introduction: why another book on family care. In: M, Nolan, U, Lundh, G, Grant and J, Keady (eds) *Partnerships in family care: understanding the caregiving career.* Maidenhead, Open University Press. pp. 1-12.

Nolan, Mike, Hanson, Elizabeth, Grant, Gordon and Keady, John (2007) *User participation in health and social care research – voices, values and evaluation.* Maidenhead, Open University Press.

Nolan, M. R. (2008) Qualitative data analysis: achieving order out of chaos. In: R, Watson, H, McKenna, S, Cowman and J, Keady (eds) *Research nursing practice: designs and methods.* Churchill Livingstone, Elsevier. pp. 341-352.

Nolan, M. R., Davies, S., Brown, J., Keady, J. and Nolan, J. (2004) Beyond 'person-centred' care: a new vision for gerontological nursing. *International Journal of Older People Nursing in Association with Journal of Clinical Nursing,* 13(3a), 45–53.

Nolan, Mike R., Grant, Gordon. and Keady, John. (1996) *Understanding family care: a multidimensional model of caring and coping*. Milton Keynes, Open University Press.

Nolan, M. R., Hanson, E., Magnusson, L. and Andersson, B. (2003b) Gauging quality in constructivist research: the Aldre Vast Sjuharad model revisited. *Quality in Ageing,* 4(2), 22-27.

Nordgren, S. and Fridlund, B. (2001) Patients' perceptions of self-determination as expressed in the context of care. *Journal of Advanced Nursing,* 35, 117-125.

O'Connell, B., Hanna, B., Penney, W., Pearce, J., Owen, M. and Warelow, P. (2001) Recovery after stroke: a qualitative perspective. *Journal of Quality in Clinical Practice,* 21, 120-125.

O'Connor, A. M., Drake, E. R., Wells, G. A., Tugwell, P., Laupacis, A. and Elmslie, T. (2003) A survey of the decision-making needs of Canadians faced with complex health decisions. *Health Expectations,* 6, 97–109.

O'Donoghue, Tom A. (2007) *Planning your qualitative research project: an introduction to interpretivist research in education.* London, Routledge.

Ohi, G. (1998) Advance directives and the Japanese ethos. In: H, M, Sass, R, M, Veatch and R, Kimura (eds) *Advance directives and surrogate decision making in health care: United States, Germany, and Japan*. Baltimore, The Johns Hopkins University Press. pp. 175–186.

Olofsson, A. Andersson, S-O. and Carlberg, B. (2005) 'If only I manage to get home I'll get better': interviews with stroke patients after emergency stay in hospital on their experiences and needs. *Clinical Rehabilitation,* 19, 433-440.

Østerlund, C. (2008) Documents in place: demarcating places for collaboration in healthcare settings. *Computer Supported Cooperative Work*, 17(2-3), 195-225.

Pandit, N. R. (1996) The creation of theory: a recent application of the grounded theory method. *The Qualitative Report* [online], 2 (4). Available from:

http://www.nova.edu/ssss/QR/QR2-4/pandit.html [Accessed 3rd January 2012]

Pang, L., Jin, S. G. and Chen, J. (2000) An analysis of the burden of hospitalisation accompanying for stroke patients. *Chinese Journal of Health Statistics,* 17(2), 93-94.

Parker, V. A. (2002) Connecting relational work and workgroup context in caregiving organizations. *The Journal of Applied Behavioural Science,* 38(3), 276-297.

Patterson, M., Rick, J., Nolan, M., Davies, S. and Musson, G. (2011) From metrics to meaning: culture change and quality of acute hospital care for older people. Report for the National Institute for Health Research Service Delivery and Organisation Programme [online]. Available from:
http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1501-93_V01.pdf
[Accessed 4th January 2013].

Patton, Michael Q. (2002) *Qualitative research and evaluation methods.* 3rd edition. Thousand Oaks, Sage.

Payne, S., Burton, C., Addington-Hall, J. and Jones, A. (2009) End-of-life issues in acute stroke care: a qualitative study of the experiences and preferences of patients and families. *Palliative Medicine* [online]. doi: 10.1177/0269216309350252. Available from: http://pmj.sagepub.com/cgi/rapidpdf/0269216309350252v1.pdf [Accessed 2nd January 2010]

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.

Phua, K. H. (1999) Comparative health care financing systems, with special reference to East Asian countries. *Research in Healthcare Financial Management,* 5(1), 111–131.

Popejoy, L. L. (2011) Complexity of family caregiving and discharge planning. *Journal of Family Nursing,* 17(1), 61–81.

Porter, S. (1991) A participant observation study of power relations between nurses and doctors in a general hospital. *Journal of Advanced Nursing*, 16, 728-735.

Proot, I. M., Crebolder, H. F. J. M., Huijer Abu-Saad, H., Macor, T. H. G. M. and Ter Meulen, R. H. J. (2000a) Stroke patients' needs and experiences regarding autonomy at discharge from nursing home. *Patient Education and Counseling,* 41, 275-283.

Proot, I. M., Huijer Abu-Saad, H., de Esch-Janssen, W. P., Crebolder, H. F. J. M. and Ter Meulen, R. H. J. (2000b) Patient autonomy during rehabilitation: the experiences of stroke patients in nursing homes. *International Journal of Nursing Studies*, 37, 267-276.

Proot, I. M., Huijer Abu-Saad, H., Oorsouw, G. G. V. and Stevens, J. J. (2002) Autonomy in stroke rehabilitation: the perceptions of care providers in nursing homes. *Nursing Ethics,* 9(1), 36-50.

Proot, I. M., Ter Meulen, R. H. J., Huijer Abu-Saad, H. and Crebolder, F. J. M. (2007) Supporting stroke patients' autonomy during rehabilitation. *Nursing Ethics,* 14(2), 229-241.

Qiu, Y. and Li, S. (2008) Stroke: coping strategies and depression among Chinese caregivers of survivors during hospitalisation. *Journal of Clinical Nursing,* 17, 1563–1573.

Rao, K. Q., Qian, J. C., Chen, H. J., Yan, X. L. and Wang, H. G. (2012) The challenge that population ageing presents to health care system and coping strategies. *Chinese Journal of Health Management*, 6(1), 6-8.

Repper, J., Nolan, M., Grant, G. and Curran, M. (2008) Family carers on the margins: experiences of assessment in mental health. *Report to the National Coordinating Centre for NHS Service Delivery and Organisation* [online]. Available from:
http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1311-053_V01.pdf
[Accessed 14th April 2013]

Rodgers, B. L. and Cowles, K. V. (1993) The qualitative research audit trail: a complex collection of documentation. *Research in Nursing and Health,* 16, 219-226.

Rodgers, H., Bond, S. and Curless, R. (2001) Inadequacies in the provision of information to stroke patients and their families. *Age and Ageing*, 30, 129-133.

Rodwell, Mary K. (1998) *Social work constructivist research.* New York, Garland.

Rogers, A. and Addington-Hall, J. (2005) Care of the dying stroke patient in the acute setting. *Journal of Research in Nursing,* 10(2), 153-167.

Rosén, P., Anell, A. and Hjortsberg, C. (2001) Patient views on choice and participation in primary health care. *Health Policy,* 55, 121–128.

Rosenbaum, J. R., Bravata, D. M., Concato, J., Brass, L. M., Kim, N. and Fried, T. R. (2004) Informed consent for thrombolytic therapy for patients with acute ischemic stroke treated in routine clinical practice. *Stroke*, 35, e353-e355.

Ross, M. M., Carswell, A., Hing, M., Hollingworth, G. and Dalziel, W. B. (2001) Seniors' decision making about pain management. *Journal of Advanced Nursing,* 35(3), 442-451.

Rotar-Pavlič, D., Švab, I. and Wetzels, R. (2008) How do older patients and their GPs evaluate shared decision-making in healthcare? *BMC Geriatrics* [online], 8: 9. Available from: http://www.biomedcentral.com/1471-2318/8/9 [Accessed 17th March 2010]

Royal College of Nursing. (2009) Research ethics: RCN guidance for nurses [online]. London, the Royal College of Nursing. Available from: http://www.rcn.org.uk/__data/assets/pdf_file/0010/78742/003138.pdf [Accessed 10th March 2010]

Royal College of Physicians Intercollegiate Working Party for Stroke. (2008) The royal college of physicians national stroke guidelines [Online]. London, RCP. Available from: http://bookshop.rcplondon.ac.uk/contents/6ad05aab-8400-494c-8cf4-9772d1d5301b.pdf [Accessed 2nd May 2011]

Royal College of Physicians Intercollegiate Stroke Working Party. (2012a) National clinical guideline for stroke [Online]. London, RCP. Available from: http://www.rcplondon.ac.uk/sites/default/files/national-clinical-guidelines-for-stroke-fourth-edition.pdf [Accessed 22nd August 2013]

Royal College of Physicians Intercollegiate Stroke Working Party. (2012b) Care after stroke or transient ischaemic attack: information for patients and their carers [Online]. London, RCP. Available from: http://www.rcplondon.ac.uk/sites/default/files/documents/care_after_stroke_or_tia_booklet.pdf [Accessed 22nd August 2013]

Ruhnke, G. W., Wilson, S. R., Akamatsu, T., Kinoue, T., Takashima, Y., Goldstein, M. K., Koenig, B. A., Hornberger, J. C. and Raffin, T. A. (2000) Ethical decision making and patient autonomy: a comparison of physicians and patients in Japan and the United States. *Chest,* 118, 1172-1182.

Ryan, G. W. and Bernard, H. R. (2000) Data management and analysis methods. In: N, K, Denzin and Y, S, Lincoln (eds) *The SAGE handbook of qualitative research.* 2nd edition. Thousand Oaks, Sage. pp. 769-802.

Rydeman, I. and Tornkvist, L. (2009) Getting prepared for life at home in the discharge process – from the perspective of the older persons and their relatives. *International Journal of Older People Nursing* [online]. doi: 10.1111/j.1748-3743.2009.00190.x. Available from: http://www3.interscience.wiley.com/cgi-bin/fulltext/122647965/PDFSTART [Accessed 18th March 2010]

Sahlsten, M. J. M., Larsson, I. E., Sjo¨stro¨m, B. and Plos, K. A. E. (2009) Nurse strategies for optimising patient participation in nursing care. *Scandinavian Journal of Caring Sciences*, 23, 490–497.

Salander, P. and Spetz, A. (2002) How do patients and spouses deal with the serious facts of malignant glaucoma? *Palliative Medicine*, 16, 305–313.

Sandberg, J., Lundh, U. and Nolan, M. R. (2001) Placing a spouse in a care home: the importance of keeping. *Journal of Clinical Nursing,* 10, 406-416.

Sarantakos, Sotirios. (1993) *Social research.* Victoria, Macmillan Education Australia.

Schneider, J. W. (1993) Family care work and duty in a modern Chinese hospital. In:

P, Conrad and E, B, Gallagher (eds) *Health and health care in developing countries: sociological perspectives.* Philadelphia, Temple University Press. pp. 154-179.

Schwandt, Thomas A. (1997) *Qualitative inquiry: a dictionary of terms.* Thousand Oaks, Sage Publications.

Scottish Intercollegiate Guidelines Network. (2010) Management of patients with stroke: rehabilitation, prevention and management of complications, and discharge planning: a national clinical guideline [online]. Edinburgh, Scottish Intercollegiate Guidelines Network. Available from:
http://www.guidelines.gov/content.aspx?id=23849 [Accessed 8th January 2013]

Seymour, J. E. and Ingleton, C. (1999) Ethical issues in qualitative research at the end of life. *International Journal of Palliative Nursing,* 5(2), 65–73.

Shepperd, S., Charnock, D. and Gann, B. (1999) Helping patients access high quality health information. *BMJ,* 319(18), 764–766.

Slingsby, B. T. (2006) Professional approaches to stroke treatment in Japan: a relationship-centred model. *Journal of Evaluation in Clinical Practice,* 12(2), 218–226.

Slot, K. B. and Berge, E. (2009) Thrombolytic treatment for stroke: patient preferences for treatment, information, and involvement. *Journal of Stroke and Cerebrovascular Diseases*, 18(1), 17-22.

Smith, K. and Biley, F. (1997) Understanding grounded theory: principles and evaluation. *Nurse Researcher,* 4, 17-30.

Smith, S. K., Dixon, A., Trevena, L., Nutbeam, D. and McCaffery, K. J. (2009) Exploring patient involvement in healthcare decision making across different education and functional health literacy groups. *Social Science & Medicine,* 69, 1805-1812.

Sneeuw, K. C. A., Aaronson, N. K., de Hann, R. J. and Limburg, M. (2007) Assessing quality of life after stroke. *Stroke,* 28, 1541-1549.

Spradley, James P. (1979) *The ethnographic interview.* New York, Holt, Rinehart and Winston.

Spradley, James P. (1980) *Participant observation.* New York, Holt, Rinehart and Winston.

Stacey, D., Menard, P., Gaboury, I., Jacobsen, M., Sharif, F., Ritchie, L. and Bunn, H. (2008) Decision making needs of patients with depression: a descriptive study. *Journal of Psychiatric and Mental Health Nursing*, 15, 287-295.

Stake, R. (2008) Qualitative case studies. In: N, K, Denzin and Y, S, Lincoln (eds) *Strategies of qualitative inquiry.* 3rd edition. Thousand Oaks, Sage. pp. 119-149.

Steeves, R. H. and Kahn, D. L. (1995) A hermeneutical human science for nursing. In A, Omery, C, E, Kasper and G, G, Page (eds) *In search of nursing science.* Thousand Oaks, Sage. pp. 175-193.

Stein-Parbury, J. and Liaschenko, J. (2007) Understanding collaboration between nurses and physicians as knowledge at work. *American Journal of Critical Care,* 16 (5), 470-478.

Stern, P. N. (1994) Eroding grounded theory. In: J, M, Morse (ed) *Critical issues in qualitative research methods.* Thousand Oaks, Sage. pp. 212-223.

Stoddart, K. (1986) The presentation of self in everyday life: some textual strategies for ‘adequate ethnography’. *Journal of Contemporary Ethnography* [online], 15(1), 103-121. Available from:
http://jce.sagepub.com/content/15/1/103.full.pdf+html [Accessed 6th March 2012]

Strauss, Anselm C. and Corbin, Juliet M. (1990) *Basics of qualitative research: grounded theory procedures and techniques.* Newbury Park, Sage Publications.

Strauss, Anselm C. and Corbin, Juliet M. (1998) *Basics of qualitative research: grounded theory, procedures and techniques.* 2nd edition. Newbury Park, Sage.

Strauss, Anselm L. (1978) *Negotiations: varieties, contexts, processes and social order.* San Francisco, Jossey-Bass.

Strong, K., Mathers, C. and Bonita, R. (2007) Preventing stroke: saving lives around the world. *The Lancet Neurology,* 6, 182-187.

Takahashi, O., Noguchi, Y., Rahman, M., Shimbo, T., Goto, M., Matsui, K., Asaia, A., Onishi, M., Koyama, H., Sawadab, I., Yoshinakab, T. and Fukui, T. (2003) Influence of family on acceptance of influenza vaccination among Japanese patients. *Family Practice,* 20(2), 162–166.

Tang, S. T., Liu, T. W., Lai, M. S., Liu, L. N., Chen, C. H. and Koong, S. L. (2006) Congruence of knowledge, experiences, and preferences for disclosure of diagnosis and prognosis between terminally-ill cancer patients and their family caregivers in Taiwan. *Cancer Investigation,* 24(4), 360-366.

Tanner, C. A., Benner, P., Chesla, C. and Gordon, D. (1996) The phenomenology of knowing the patient. In: S, Gordon, P, Benner and N, Noddings (eds) *Caregiving: readings in knowledge, practice, ethics and politics.* Pennsylvania, University of Pennsylvania Press. pp. 203-225.

Taylor, Steven J. and Bogdan, Robert. (1984) *Introduction to qualitative research methods: the search for meanings.* 2nd edition. New York, John Wiley & Sons.

The Central Party Committee and The State Council. (1997) Decisions on health sector reform and development [online]. Beijing, The Central Party Committee and The State Council. Available from: http://www.moh.gov.cn/publicfiles/business/htmlfiles/wsb/pM30115/200804/18540.htm [Accessed 16th January 2011]

The Central People’s Government of the People’s Republic of China. (2005) The Chinese Constitution [online]. Available from: http://www.gov.cn/ziliao/flfg/2005-06/14/content_6310_3.htm [Accessed 24th March 2012]

The State Council. (2000) Guidelines for reforming the urban health and pharmaceutical sectors [online]. Beijing, The State Council. Available from: http://www.shui5.cn/article/2d/46311.html [Accessed 16th January 2011]

The State Council. (2007) Guiding opinions of the State Council about the pilot urban resident basic medical insurance [online]. Beijing, The State Council. Available from:

http://www.gov.cn/zwgk/2007-07/24/content_695118.htm [Accessed 16th January 2011]

Tian, G. (2011) Application of Chairman Mao's policy of the integration of traditional Chinese medicine and western medicine after establishment of the Republic of China. *Journal of Capital University of Medical Sciences (Social Science Edition Supplement),* 7-9

Tian, L. (2007) Basic healthcare for all by 2020 [online]. China Daily, Friday October 19 2007, p.1. Available from:
http://www.chinadaily.com.cn/business/2007-10/19/content_6189506.htm
[Accessed 16th January 2011]

Tianjin Daily. (2010) Ageing population in Tianjin [online]. Tianjin Daily, Sunday July 11 2010, p.1. Available from:
http://www.chinadaily.com.cn/dfpd/tianjin/2010-07-11/content_562383.html
[Accessed 16th January 2011]

Tianjin Municipal Government. (2001) The regulation of basic health insurance for urban employees in city of Tianjin [online]. Tianjin, Tianjin Municipal Government. Available from: http://www.feesco.com.cn/zcfg/system/2006/04/05/000001569.shtml [Accessed 16th January 2011]

Tianjin Municipal Tourism Bureau (2009) *Tianjin travel guide*. Tianjin, Tianjin Municipal Tourism Bureau.

Tong, X. Y. and Qi, Y. (2005) Influence of the differences of role, gender, educational level and resident place on mental health in the relatives of stroke patients. *Chinese Clinical Rehabilitation,* 9, 14–15.

Trojan, L. and Yonge, O. (1993) Developing trusting, caring relationships: home care nurses and elderly clients. *Journal of Advanced Nursing,* 18, 1903–1910.

Tsai. D. F. C. (1999) Ancient Chinese medical ethics and the four principles of biomedical ethics. *Journal of Medical Ethics,* 25, 315–321.

Tuckett, D., Boulton, M., Olson, C. and Williams, A. (1985) *Meetings between* *experts: an approach to sharing ideas in medical consultations*. London, Tavistock Publications.

Turnock, C. and Gibson, V. (2001) Validity in action research: a discussion on theoretical and practice issues encountered whilst using observation to collect data. *Journal of Advanced Nursing*, 36, 471–477.

Tutton, E. M. M. (2005) Patient participation on a ward for frail older people. *Journal of Advanced Nursing*, 50(2), 143–152.

UK Parliament. (1998) Data protection act [onlind]. London, Her Majesty's Stationery Office (HMSO). Available from: http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_1 [Accessed 10th March 2010]

Van Essen, G. A., Kuyvenhoven, M. M. and de Melker, R. A. (1997) Compliance with influenza vaccination. *Archives of Family Medicine*, 6, 157–162.

Vincent, J. L. (1999) Forgoing life support in western European intensive care units: the results of an ethical questionnaire. *Critical Care Medicine*, 27, 1626-1633.

Walker, E. and Dewar, B. J. (2001) How do we facilitate carers' involvement in decision making? *Journal of Advanced Nursing*, 34(3), 329-337.

Wang, L. D. (2012) Strategies for and practice of prevention and management of stroke. *Health Care of Middle-aged and Older People*, 1, 8-9.

Wang, V. and Marsh, F. H. (1992) Ethical principles and cultural integrity in health care delivery: Asian ethnocultural perspectives in genetic services. *Journal of Genetic Counseling*, 1(1), 81-92.

Wang, Y. (2009) *The concept of clinical decision making among baccalaureate-prepared nurses in mainland China: an exploratory study.* MPhil Thesis, Chinese University of Hong Kong.

Watson, H. and Whyte, R. (2010) Using observation. In: K, Gerrish and A, Lacey (eds) *The research process in nursing.* 6th edition. Oxford, Wiley-Blackwell. pp. 383-398.

Wei, B. H. and Chen, Z. S. (2011) New understanding, new starting point and new motivation. *Tianjin Journal of Traditional Chinese Medicine*, 28(2), 89-92.

Wei, J. W., Heeley E. L., Jan, S., Huang, Y. N., Huang, Q. F., Wang, J. G., Cheng, Y., Xu, E., Yang, Q. D. and Anderson, C. S. (2010) Variations and determinants of hospital costs for acute stroke in China. *PLoS ONE,* 5(9), 1-9.

Wellard, S. J., Lillibridge, J., Beanland, C. and Lewis, M (2003) Consumer participation in acute care settings: an Australian experience. *International Journal of Nursing Practice,* 9, 255–260.

Wellwood, I., Dennis, M. S. and Warlow, C. P. (1994) Perceptions and knowledge of stroke among surviving patients with stroke and their carers. *Age and Ageing,* 23(4), 293-298.

Weng, L., Joynt, G. M., Lee, A., Du, B., Leung, P., Peng, J., Gomersall, C. D., Hu, X., Yap, H. Y. and The Chinese Critical Care Ethics Group. (2011) Attitudes towards ethical problems in critical care medicine: the Chinese perspective. *Intensive Care Medicine,* 37, 655–664.

WHO. (2000) The world health report 2000: health systems: improving performance [online]. Geneva, WHO. Available from:
http://www.who.int/whr/2000/en/whr00_en.pdf [Accessed 16th January 2011]

WHO. (2005) Social health insurance: selected case studies from Asia and the Pacific [online]. Geneva, WHO. Available from:
http://www.wpro.who.int/NR/rdonlyres/8EE02A82-B0EF-4EE3-B635-465A7C67794D/0/searpno42.pdf [Accessed 16th January 2011]

Wiles, R., Pain, H., Buckland, S. and McLellan, L. (1998) Providing appropriate information to patients and carers following stroke. *Journal of Advanced Nursing,* 28 (4), 794-801.

Williams, S. (2001) *Grasping the nettle, understanding hospital discharge: a constructivist inquiry.* PhD Thesis, University of Wales.

Williams, S., Nolan, M. and Keady, J. (2009) Relational practice as the key to ensuring quality care for frail older people: discharge planning as a case example. *Quality in Ageing*, 10(3), 44-55.

Wilson, S., Morse, J. and Penrod, J. (1998) Developing reciprocal trust in the caregiving relationship. *Qualitative Health Research,* 8, 446–465.

Wong, T. K. S. and Pang, S. M. C. (2000) Holism and caring: nursing in the Chinese health care culture. *Holistic Nursing Practice*, 15(1), 12-21.

Wu, B., Liu, M., Liu, H., Li, W., Tan, S., Zhang, S. and Fang, Y. (2007) Meta-analysis of traditional Chinese patent medicine for ischemic stroke. *Stroke*, 38(6), 1973-1979.

Wu, H. M., Tang, J. L., Lin, X. P., Lau, J. T. F., Leung, P. C., Woo, J. and Li, Y. (2006) Acupuncture for stroke rehabilitation. *Cochrane Database of Systematic Reviews* [online], Issue 3. Art. No.: CD004131. DOI: 10.1002/14651858.CD004131.pub2. Available from: http://www.thecochranelibrary.com/userfiles/ccoch/file/Acupuncture_ancient_traditions/CD004131.pdf [Accessed 16th January 2011]

Wu, Y. R. (1997) China’s health care sector in transition: resources, demand and reforms. *Health Policy,* 39, 137-152.

Xie, H., Zhang, X. N. and Shi, H. Y. (2000) A study on burden and factors affecting caretakers of apoplexy in patients. *Chinese Nursing Research,* 14, 233–235.

Xu, L., Wang, Y., Collins, C. D. and Tang, S. L. (2007) Urban health insurance reform and coverage in China using data from National Health Services Surveys in 1998 and 2003. *BMC Health Services Research,* 7, 37.

Xu, R., Li, X. Y. and Zeng, T. Y. (2005) Domestic situation and progress in hospital administration of caregiver. *Journal of Nursing Science,* 20, 75–77.

Yang, C. C., Yang, Y. and Yin, A. T. (2010) The analysis on the current medical insurance system in China. *Qingdao Medical Journal,* 42(1), 52-55.

Yang, T. and Leng, M. X. (2010) Optimising health care insurance system for older people in China. *Chinese Journal of Gerontology,* 30(1), 121-123.

Yap, H. Y., Joynt, G. M. and Gomersall, C. D. (2004) Ethical attitudes of intensive care physicians in Hong Kong: questionnaire survey. *Hong Kong Medical Journal,* 10(4), 244-250.

Yeates, G., Henwood, K., Gracey, F. and Evans, J. (2007) Awareness of disability after acquired brain injury and the family context. *Neuropsychological Rehabilitation: An International Journal,* 17(2), 151-173.

Yin, Robert K. (1989) *Case study research: design and methods.* London, Sage.

Yun, Y. H., Lee, C. G., Kim, S. Y., Lee, S. W., Heo, D. S., Kim, J. S., Lee, K. S., Hong, Y. S., Lee, J. S. and You, C. H. (2004) The attitudes of cancer patients and their families toward the disclosure of terminal illness. *Journal of Clinical Oncology,* 22, 307-314.

Zhang, H., Feng, Z. Y., Hu, Y. S., Wang, B. L. and Qian, X. L. (2004) Effects of home-based rehabilitation nursing intervention on caring ability of stroke patients' family carers. *Journal of Nurses Training,* 19(1), 7-10.

Zhang, Q., Zhu, L. and Wim, V. D. L. (2011) The importance of traditional Chinese medicine services in health care provision in China. *Universitas Forum* [online], 2(2). Available from: http://www.universitasforum.org/index.php/ojs/article/view/63/242 [Accessed 24th March 2012]

Zhang, Q. W., Chen, X. Y., Wang, F., Fan, Z. Y., Zhou, Y., Liu, Y., Wang, H. Q., Wan, X. L., Dong, X. X., Liao, H., Liu, G. J. and Zhang, M. M. (2008) A survey of doctors' perceptions of difficulties in patient participation in clinical decision making. *Medicine and Philosophy (Clinical Decision Making Forum Edition),* 29(4), 1-2, 4.

Zhang, Q. W., Wan, S. L., Liu, Y., Dong, X. X., Wang, H. Q., Wang, F., Zhou, Y., Fan, Z. Y., Chen, X. Y. and Zhang, M. M. (2010) A survey of patients' perceptions of participation in shared decision making. *Chinese Journal of Evidence-based Medicine,* 10(1), 10-13.

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.

Zhang, Z. W. and Shen, A. Z. (2004) Comparison of national basic medical insurance medicine list and national basic medicine list. *Chinese Health Service Management,* 5, 317-318.

Zhu, H. (2000) *A contrastive study of politeness language in Chinese and English* [online]. MSc Thesis, Jinlin University. Available from: http://202.198.25.8:8080/was40/paperpdf/3000114.pdf [Accessed 10th December 2009]

Zhu, Y. and Cheng, Y. P. (1997) Kinship and legal duties in ancient China. *Social Sciences in China*, 18(2), 99–105.

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 heave 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

Step	**Search term**	**Number of articles retrieved**
1	*decision making/ or *choice behaviour/ or *consensus/ or *negotiating/	35831
2	limit 1 to (english language and yr="1980 - 2010")	27434
3	*Patients/	9171
4	limit 3 to (english language and yr="1980 - 2010")	5492
5	*Family/	24729
6	limit 5 to (english language and yr="1980 - 2010")	17284
7	*Caregivers/	12481
8	limit 7 to (english language and yr="1980 - 2010")	9756
9	*Patient Participation/	8421
10	limit 9 to (english language and yr="1980 - 2010")	6809
11	*Health/	8356
12	limit 11 to (english language and yr="1980 - 2010")	4652
13	2 and 4	197
14	2 and 6	479
15	2 and 8	165
16	4 and 10	70
17	6 and 10	99
18	8 and 10	39
19	12 and 13	1
20	12 and 14	0
21	12 and 15	0
22	12 and 16	2
23	12 and 17	0
24	12 and 18	0
25	decision making/ or choice behavior/ or consensus/ or negotiating/	86554
26	limit 6 to (english language and yr="1980 - 2010")	67841
27	brain ischemia/ or "intracranial embolism and thrombosis"/ or intracranial haemorrhages/ or stroke/ or brain infarction/	86169
28	limit 8 to (english language and yr="1980 - 2010")	61235
29	26 and 28	233

Appendix 3 Characteristics of Studies on Health Care Decision-Making (n=20)

Author, year of publication, country	Aim(s)	Sample (age, gender, ethnicity) and setting	Design	Data collection and analysis	Rigour	Results	Summary of major limitation
Arora and McHorney (2000) the US	To identify the determinants of patient preferences for participation in medical decision making (DM).	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)	Cross-sectional observational quantitative study	Participation preference, socio-demographics, diag., severity, coping, social support, health distress or value, will to function, lifestyle analysed statistically.	Cronbach's alpha and skewness were calculated.	69% of the patients preferred a passive role--to leave 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.	Single-item dependent variable measure is less reliable than multi-item scale, and is only measured once.
Biley (1992) the UK	To discover how patients feel about participating in DM about nursing care.	4 male and 4 female informants who had undergone surgical procedures under anaesthesia, aged between 21 and 75.	Cross-sectional qualitative study using modified grounded theory method	Unstructured, open-ended interviews and qualitative data analysis.	Not reported	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 participated 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/encourages 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.	Sample size was small, there was no structured sampling plan, and data saturation was not achieved. Strategies for ensuring trustworthiness of data were not known.
Deber et al. (2007) Canada	To examine the role patients would prefer in making treatment decisions across multiple clinical settings.	2754 patients with breast cancer, prostate disease, fractures, continence, orthopaedic, rheumatology, multiple sclerosis, HIV/AIDS, infertility, benign prostatic hyperplasia, cardiac disease, and healthy nursing students (mean age 52.2, age range 16-88, male 60.2%).	Cross-sectional quantitative study	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.	Not reported	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).	Secondary analysis. No information about validity and reliability testing.
Elwyn et al. (1999) the UK	To explore the views of general practice registrars about	A purposive sample of 39 general practice registrars and 8 course organisers	Cross-sectional qualitative	Doctors conducted and observed the consultations with	Not reported	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	The use of simulated patients didn’t reflect

	involving patients in decisions, and to assess the feasibility of using shared DM model by means of simulated general practice consultations.	(acting as observers) from general practice vocational training schemes attended 4 focus groups.	study	simulated patients. Then focus groups were conducted to explore their views on involving patients in decisions. Content analysis.		data, decision situations for urgent/dangerous problems/situations of conflict, lack of time, biased presentation of info., lack of training in skills required to involve pts, pts' potential anxiety, not asking pts preferred role. Participants viewed shared DM as a process, and it's important to achieve the correct or appropriate 'timing' for involving patients. Participants thought that successful patient involvement was explicitly indicating involving patient in DM, exploring their views, and clearly and appropriately presenting all choices available.	"actual" practice. No information about trustworthiness of data and finding
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±16.5, age range 23–84). 35 RNs had a median age of 31.	Longitudinal comparative quantitative study.	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 for needs in communication, breathing, skin, sleep 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.	Non-random small sample of relatively healthy patients from one ward influenced generalizability. Using one single assessment influenced reliability and validity. No reliability and validity testing.
Fraenkel and McGraw (2007a) the US	To understand how patients view their involvement in health care DM.	A consecutive sample of 26 participants. (25 women and 1 man, mean age 61, age range49–76, all were Caucasian)	Cross-sectional qualitative study	Semi-structured interviews and constant comparative analysis	Not reported	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.	No purposive sampling; limited sample influencing generalizability. No information about trustworthiness.
Fraenkel and McGraw (2007b) the US	To understand essential elements or prerequisites critical to active patient participation in medical DM from patient's perspective.	A consecutive sample of 26 community dwelling subjects. (25 women and 1 man, mean age 61, range 49-76, all were Caucasian)	Cross-sectional qualitative study	Semi-structured interviews and constant comparative analysis.	Not reported	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.	Sample was limited influencing generalizability. No information about trustworthiness of data and finding.
Hallstro¨m and Elander (2004) Sweden	To explore what kind of decisions and how these decisions were made during a child's hospitalization.	A purposive sample of 24 children, 35 parents and 3 other relatives from 7 units: emergency, infectious diseases, neurology, endocrinology, oncology, cardiology and	Cross-sectional qualitative study	Non-participant observations and qualitative data analysis with field notes being analysed by manifest and latent	2 observers performed the fieldwork to enhance validity, without personal	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	No information about limitation reflection and validity testing.

		surgery. Among children, 2 female and 22 male, aged 5 months – 8 years; among families, 23 female and 15 male, 22 mothers, 13 fathers, 2 brothers, and 1 grandmother.		coding.	involvement, without transferring information from them to staff.	10 satiations. Professionals made decisions alone in 106 situations. Decisions were made in mutual agreement between children, parents and staff in 99 situations. Although children and parents disagreed with the decision made in 83 of the 218 situations, decisions were seldom reconsidered.	
Henderson and Shum (2003) Hong Kong	To explore the extent to which Hong Kong Chinese population desires to participate in treatment DM about surgical intervention.	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±1.56, 38 female and age 20.34±0.88.	Cross-sectional quantitative study	Participants were given 3 scenarios: cardiac failure needing major surgery; cholecystitis needing routine surgery; and skin lesion needing minor surgery, and asked preferences.	Validity was supported by correlating ratings using cards, with ratings using questionnaire. Cronbach's alpha was calculated.	When the medical condition is not severe, collectively the student and patient group desired greater participation in the DM process. Younger participants desired greater collaboration with doctor in DM. Older participants preferred the doctor to have greater input in DM. Patient sample desired greater participation by the doctor in DM than student group.	Convenience small sample.
Kelly-Powell (1997) the US	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.	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 centre, and a family practice in rural area (9 men and 9 women, 15 Caucasian, 2 African–American, and 1 native American).	Cross-sectional qualitative study using grounded theory method.	Data included verbatim open-ended interview transcriptions and field notes. Data were analyzed using constant comparative analysis.	Reflexive journal, prolonged interviews, repeated contacts, peer debriefing, purposive sampling, and member checking.	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.
Larsson et al. (2007) Sweden	To explore the meaning of patient participation in nursing care from a patient point of view.	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)	Cross-sectional qualitative study using grounded theory method	Focus group interviews and constant comparative analysis.	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.	Holding 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.
Levinson et	To explore public	A nationally representative	Cross-	General Social	Not reported	Nearly all respondents (96%) preferred to be offered choices and to be	No information

al. (2005) the US	preferences for participation in DM, and how socio-demographic variables and health status influence people's preferences.	sample of 2750 English-speaking adults. (56% female, mean age 46±17.4, 78.2% White, 14.5% African-American and 7.3% Hispanic)	sectional quantitative study using a population-based survey	Survey was conducted in face-to-face interviews. Respondents expressed preferences for participation. Statistical analysis was used.		asked their opinions by doctors. In contrast, half of the respondents (52%) preferred to leave final decisions to their physicians and 44% preferred to rely on physicians for medical knowledge rather than seeking out information themselves. Women, more educated, and healthier people were more likely to prefer an active role in DM. African-American and Hispanic respondents and people with a regular doctor were more likely to prefer that physicians make the decisions. Preferences for an active role increased with age up to 45 years, but then declined.	about validity and reliability testing. Only English speaking and public sample was used, influencing the generalizability of findings.
Lown et al. (2009) the US	To explore how patients and physicians working together describe attitudes and behaviours that facilitate shared medical DM.	85 patients with chronic conditions and primary care physicians and age range 34-79. 41 physicians, 20 women and 21 men. 44 patients, 29 women and 15 men, with chronic conditions: diabetes, hypertension, rheumatoid arthritis, congestive heart failure, liver transplant and chronic leukaemia.	Cross-sectional qualitative study using grounded theory method	Focus group discussion was recorded, and the descriptions and transcriptions were analyzed using constant comparative analysis.	Not reported	Participants described a dynamic DM process where patients and physicians had similar attitudes and behaviours and influenced each other. 1. Pts and physicians needed to actively seek a personal connection with each other over time, trust, respect and offer empathy to one another, actively build a relationship that made shared DM possible. 2. Participants recognized the importance for patients to express preferences and needs, and for physicians to explore patient's preferences. 3. Patient and physician needed to discuss information and options. 4. Patients and physicians needed to actively seek information, support and advice from family, loved ones, friends and trusted colleagues. 5. Pts and physicians needed to negotiate a decision in a dynamic process where either physician or patient might assume, defer or share control. 6. Ultimate responsibility for implementing decision resides with patients.	No information about trustworthiness. Only primary-care physicians and patients with serious/chronic conditions were recruited, influencing the generalizability.
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.	A random sample of 255 patients from outpatient medical clinic. (age 63.2±10.5, 95.2% male, 61.9% married, 97.1% white)	Cross-sectional quantitative study	Exploring patients' responses to simulated illnesses (cancer, AMI, and diabetes), survey about DM and chart review about comorbidity. Statistic analysis.	Factor analysis used to examine validity, and Cronbach's alpha was calculated for internal consistency reliability.	Patients wanted to share hypothesized major decisions with their physicians but wanted less involvement in hypothesized minor decisions. The patients preferred to share DM with the physician for decisions about altering their own behaviours, such as smoking, diet, and exercise. Patients with recent severe heart disease (myocardial infarction, bypass surgery, angioplasty) wanted more involvement in decisions about acute myocardial infarction than did patients with stable angina or no heart disease. Prior experience with diabetes did not affect decisions about diabetes. No effect of comorbid illness severity or pre-existing psychiatric illness (depression and anxiety) on patients' desire for DM.	Differences between responders and non-responders were not known. Participants were predominantly white and male, influencing the generalizability.
O'Connor et al. (2003) Canada	To describe DM needs of Canadians when faced with 'complex' health decisions characterized by balancing advantages against disadvantages.	A randomized national sample of 635 adults. (Age 18–24, 11%; 25–29, 7%; 30–39, 23%; 40–49, 22%; 50–59, 17%; 60–69, 9%; 70 or more, 9%. Male, 35%; female, 65%. Home language, English, 73%; French, 20%; Chinese, 0.6%; Italian, 0.3%; Other, 6%)	Cross-sectional quantitative study using telephone survey with random digit dialing.	Structured telephone interview using a series of closed- and open-ended questions and statistical analysis	Not reported.	65% of 635 participants reported making 'complex' decisions, more frequently reported by women and married or separated individuals. Most respondents took an active DM role. Being younger was associated with a more independent role. Physicians were more often involved in decisions of respondents with less education. 59% of respondents experienced decisional conflict; more conflict was seen with those who were female and feeling uninformed about options, pressured to select one particular option, and unready or unskilled in DM. Less decisional conflict was seen in those who reported birth control decisions and in those who were 70 years and older. Participants used several strategies when deliberating about choices	High refusal rate and not knowing non-participants' experiences. Imbalanced sample. Bias in reporting socially acceptable decisions, recall bias, and hindsight bias.

						including: information gathering, clarifying values, and seeking support.	
Rosén et al. (2001) Sweden	To identify patients' individual preferences for choice and shared DM.	1543 primary care patients. (47% age 60 or older; 581 male, mean age 58.4, 973 female, mean age 52.7)	Cross-sectional quantitative study	Self-administered questionnaire survey and statistical analysis	Not reported.	1. Choice of primary-care physician 3/4 of respondents wanted to choose their physician. Older groups were more strongly advocate free choice than those aged 30 or younger. 2. Possession of information 60% of pts aged 71 or older agreed they were adequately informed, but only 21% of youngest agreed. Only 4% of the oldest didn't agree they possessed sufficient info., 46% of pts aged 30 or younger didn't agree. Pts aged below 40 with primary/high school education felt better informed than similarly aged with university education. Among pts who judged health as being better, 57% agreed that they are sufficiently informed, only 37% of those who regarded health as worse agreed fully. 3. Choice of treatment alternative A majority of respondents favoured shared DM in this area. Young and higher education respondents preferred a higher degree of participation.	No information about validity and reliability testing. Not know whether use random sample.
Sahlsten et al. (2009) Sweden	To explore RNs' strategies to stimulate and optimise patient participation in nursing care.	A purposive sample of 16 experienced RNs in inpatient somatic care. (all female, from rehabilitation, gynaecological, orthopaedic, eye and medical wards)	Cross-sectional qualitative study	Focus group interview and content analysis	Subcategories and categories were discussed by researchers to increase credibility.	1. Building close cooperation means establishing collaboration with pt as a valued co-worker. Nurses needed to trust pts' ability, respect pts' own opinions/experiences, show courage to release control. 2. Getting to know the person means nothing is taken for granted, and nurses know the pt as a person. Nurses needed to focus on listening to pts' expressions and use stimulating questions to elicit experiences. 3. Reinforcing self-care capacity means nurses support pts to identify and use their own resources, strengths, and full potential. Nurses needed to help pts to work out manageable goals, to overcome difficulties and make progress, and to encourage pts and build up their self-confidence.	Small number of informants in focus groups. The setting was limited to inpatient somatic care.
Smith et al. (2009) Australia	To explore understandings and experiences of involvement in DM among patients varying in education and functional health literacy.	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)	Cross-sectional qualitative study using phenomenology	Semi-structured interview and thematic analysis. Functional health literacy measures were used.	Not reported.	Participants with various education perceived involvement differently. 1. Higher education participants conceived involvement as sharing responsibility with dr., verifying credibility of information, exploring options, helping others family or friends in DM as information resources. 2. Lower education participants conceived involvement as consenting to an option recommended by dr., having responsibility for final decision, agreeing/disagreeing with recommendation. They valued that relatives and friends sought information for them in their DM. 3. Both groups described how pt–practitioner relationship and profs' interpersonal communication skills influenced their involvement. 4. Health information supported psychosocial, practical and decision support needs for all groups.	Not knowing the influence of gender, ethnicity, and the experience of people with basic literacy skills. No information about trustworthiness and validity and reliability testing.
Zhang et al. (2008) China	To explore doctors' perceptions of difficulties in patient participation in clinical DM.	A random sample of 259 doctors in medical, surgical and other settings of an acute care hospital (169 male and 90 female).	Cross-sectional quantitative study	Self-administered questionnaire survey and statistical analysis	Not reported.	Major difficulties for patient to be involved in DM concerning: doctors' lack of time to communicate with patients; difficulties to establish a stable trusting relationship with patients, to cooperate with patients and share responsibilities, to provide reliable information to patients, to provide best possible treatment choices to meet patients' needs, to effectively communicate with patients in order to elicit their preferences, and to	No information about validity and reliability testing.

						inform patients about uncertainty and risk of treatment interventions.	
Zhang et al., (2010) China	To explore patients' perceptions of participation in shared DM.	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).	Cross-sectional quantitative study	Self-administered questionnaire survey and statistical analysis	Not reported.	A majority of patients preferred to actively participate in DM, and receive information relevant to treatment from doctors, medical journals or internet. They also preferred doctors to ask their preferences when they made treatment decisions. Lack of time to communicate with doctors was identified as the major barrier to their participation in DM.	No information about validity and reliability testing.

Appendix 4 Characteristics of Studies on Health Care Decision-Making with Older People and Their Families (n=15)

First author, year of publication, country	Aim(s)	Sample (age, gender, ethnicity) and setting	Design	Data collection and analysis	Rigour	Results	Summary of major limitation
Belcher et al. (2006) the US	To explore the views or the perceptions of older adults regarding patient participation/involvement in medication decision making (DM).	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).	Cross-sectional qualitative study	Semi-structured interview and constant comparative analysis	Not reported	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.	Participants from limited setting, not knowing perceptions of non-participants. Strategies for ensuring trustworthiness of data were not known.
Bogardus et al. (2001) the US	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.	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).	Cross-sectional survey	Telephone interview with caregivers, self-administered questionnaire finished by physicians, and statistical analysis.	Not reported	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.	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.
Chang et al. (2008) Korea	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.	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).	Cross-sectional quantitative study	Individual interview with participants using questionnaire, and statistical analysis.	Not reported	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 & 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.	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.
Davies and Nolan (2003) the UK	To explore the experiences of decisions about nursing home entry or placements from the viewpoint of	A convenience sample of 37 people who had assisted a close relative to move into a nursing home (24 female and 13 male).	Cross-sectional qualitative study using constructivist approach	Semi-structured interview and analysis using constructivist method	Member checking	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	Convenience sample

	relatives.					determined largely by the interaction of 5 perceived continuous dimensions, including: operating ‘under pressure’ or ‘not’; ‘in the know’ or ‘working in the dark’; ‘working together’ or ‘working alone’; ‘in control of events’ or not, and ‘supported’ or ‘unsupported’ both practically and emotionally.	
Hasselkus (1992) the US	To explore the family caregiver-professional relationship by examining interactions between physicians and family caregivers in a medical care setting.	40 clinical visits involving 27 older patients, 31 family caregivers, and 11 physicians in the general internal medicine and geriatric clinics (patient mean age 77.3 age range 64-91; caregiver age range 36-86, 22 female and 9 male).	Cross-sectional qualitative study	Clinical visits were audio-taped and qualitatively analyzed	Not reported	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.	Small sample size, not knowing non-participants’ interactions in medical setting. No information about trustworthiness of data and finding.
Jewell (1996) the UK	To explore primary nurses' perceptions of patient participation in discharge DM (discharge planning).	A convenience sample of 9 primary nurses from 2 elderly care units specializing in rehabilitation.	Cross-sectional qualitative study	Focus group interview and content analysis	Not reported	Nurses used nursing process as a practical form of patient participation, which was regarded as seeing what patient wants and self-care. The individualized or holistic patient-centred care, the need to make realistic plans, and encouraging patients to be active were philosophical understanding of patient participation. 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.	Convenience sample, no information about trustworthiness of data and finding.
Kao and Stuifbergen (1999) Taiwan	To explore family members’ experiences related to the decision to institutionalize an elderly member in Taiwan.	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).	Cross-sectional qualitative study	Semi-structured interview and content analysis	Member checking	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.	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.
Lundh et al. (2000) Sweden	To explore the experiences of Swedish spouses who have placed a partner in a care home for older people.	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).	Cross-sectional qualitative study	Semi-structured interview and constant comparative analysis	Not reported	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	Limited sample influenced generalisability. Strategies for ensuring trustworthiness of data were not known.

						accusation. Informants had ambivalent emotional reactions to the placement, including feeling like an `outsider' with powerlessness, concerning about the standard of care, or feeling sense of freedom from physical caring. Informants tried to establish new patterns of interaction and contact and get involved in caring.	
Menne and Whitlatch (2007) the US	To consider the stressors and strains associated with having cognitive impairment, and to explore the predictors of decision-making involvement among individuals with dementia.	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).	Cross-sectional quantitative study	Using DM involvement scale, values and preferences scale, and conducting statistical analysis	Not reported	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.	No validity & 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.
Nolan and Dellasega (2000) the UK	To explore placing a relative in a nursing home from a carer's perspective.	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).	Cross-sectional mixed quantitative & qualitative study	A largely structured, interviewer-administered questionnaire survey including both qualitative and quantitative data collection, and using content analysis and statistical analysis	Not reported	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 in the US. Drs made final decision in about 25% cases in both countries, social worker in the UK was more likely to make final decision.	Non-random sample influenced generalisability. No information about validity and reliability testing, and trustworthiness of data and finding.
Ross et al. (2001) Canada	To investigate seniors' DM regarding the management and control of musculoskeletal pain.	A convenience 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).	Cross-sectional exploratory-descriptive study, and primarily using qualitative method.	Focus group interview and mail back questionnaire, content analysis and statistical analysis	Data from questionnaire provided validation for qualitative data	Participants made decisions within a context of ageing and health and social consequences of advancing age, and their beliefs and expectations about ageing 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.	Convenience sample influenced generalisability.
Rotar-Pavlič et al. (2008) Slovenia	To analyze perceptions of patient involvement in	A stratified sample of 39 older patients at home or health centres, and 26	Cross-sectional qualitative	Semi-structured interview and content analysis	Validation: 5 texts of both samples	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	No other strategies to ensure trustworthiness were reported.

	shared DM in health care by elderly patients and their GPs in family medicine in Slovenia.	physicians in remote areas, private practice, public health care sector, school, and partner or group practices (patients age range 70-95).	study		were analyzed, demonstrated good congruity. International consistency of coding evaluated.	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.	
Rydeman and Tornkvist (2009) Sweden	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.	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).	Cross-sectional grounded theory study	Semi-structured interview and constant comparative analysis	Writing memo. Member checking. Trying to entering research with few pre-conceptions.	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.	Researchers might have preconceptions. Voluntary participation might yield a sample with strong views about discharge. Limited setting influenced the generalisability.
Tutton (2005) the UK	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.	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.	Action research	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.	Not reported.	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.	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.
Walker and Dewar (2001) the UK	To investigate the extent to which carers were involved in decisions relating to care planning.	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.	Cross-sectional qualitative case study	Individual or focus group interview, non-participant observation, documentation, and constant comparative analysis.	individual researchers analysed data independently with a view to subsequent discussion, this provided	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 processes, 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.	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)

Author, year of publication, country	**Aim(s)**	**Sample (age, gender, ethnicity) and setting**	**Design**	**Data collection and analysis**	**Rigour**	**Results**	**Summary of major limitation**
Alaszewski et al. (2008) The UK	To understand health professionals' information provision about stroke.	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)	Cross-sectional	Individual interview and focus group and qualitative analysis	No information about strategies to ensure validity and reliability.	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.	Small sample size, no strategies taken to ensure validity and reliability.
Andersson and Hansebo (2009) Sweden	To explore older stroke patients' experiences about nursing care from a gender perspective.	A convenience sample of 5 male and 5 female older patients aged between 66 and 75 years from a stroke rehabilitation ward in Sweden.	Cross-sectional	Open-ended interview and content analysis	Fewer strategies to ensure trustworthiness: giving sufficient information about data analysis procedures, having discussion and comparison during data analysis.	Both men and women reported lack of participation in care planning; women wanted professionals to make decisions for them; men question professionals' decisions and give suggestions, or stick to their own decisions through negotiating with professionals.	Convenience sample and only one ward used to recruit participants influenced transferability,
Brereton and Nolan (2002) the UK	To explore the perceptions of health care providers regarding who is responsible for selected role functions in decision making.	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)	Longitudinal prospecive study	Semi-structured interview and constant comparative analysis	Member checking	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.	Limited strategies used to ensure validity and reliability.
Brereton and Nolan (2003) the UK	To understand the experiences of new carers of stroke survivors.	A purposive sample of 18 new British family carers (8 male, 10 female; aged 32-93).	Longitudinal prospective study	Semi-structured interview and constant comparative analysis	Member checking	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.	Limited strategies used to ensure validity and reliability.
Gibson (2002) the UK	To explore decision making in carotid endarterectomy from patient's and surgeon's perspectives.	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).	Cross-sectional, Grounded theory study	Semi-structured interview and constant comparative analysis	No information about strategies to ensure validity and reliability.	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.	Small and convenience sample size, no strategies taken to ensure validity and reliability.
Hedberg et	To investigate how	14 care-planning meetings were	Cross-	Audio-recorded	Inter-rater	3 types of communication during decision making included	Limited sample

al. (2008) Sweden	stroke survivors, relatives, and professionals communicate and make decisions about patient care after discharge.	held in 1 geriatric rehabilitation ward at a hospital, and at 3 rehabilitation centres.	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 summarizing; 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.	size influenced transferability.
Hjelmblink (2008) Sweden	To explore meaning of life after stroke from patients’ points of view.	19 older Swedish stroke patients aged between 56 and 89 during the first year post stroke (8 male, 11 female).	Cross-sectional	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.	Limited sample size and strategies of ensuring validity and reliability.
Huby et al. (2007) the UK	To investigate how older patients and professionals understand decision making about discharge planning after acute hospitalization, and how practice influences their decision making.	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.	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.	Lack of strategies to testing validity and reliability.
Mangset et al. (2008) Norway	To explore factors influencing stroke patients’ satisfaction with rehabilitation following stroke.	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).	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.	Patients were not willing to express negative attitudes. Small sample size, limited setting influenced transferability.
Marques et al. (2006) Brazil	To investigate changes of family relations occurred after patients suffered	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	Cross-sectional	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’	Lack of strategies to testing validity and reliability.

	from stroke.	patients).				decision making power, and involvement of all relatives in decision making gave patients more sense of security.	
Moloczij et al. (2008) New Zealand	To investigate decision making about help-seeking at the time of stroke.	20 stroke survivors aged between 46 and 88 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	Cross-sectional Retrospective grounded theory study	Interview and constant comparative analysis	Using independent researcher to analyze data, and using team meeting to discuss data analysis, in order to ensure rigour.	Participants went through a decision making 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.	Limited sample and setting influenced transferability.
Olofsson et al. (2005) Sweden	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.	9 Swedish patients aged between 64 and 83 years and 5 families in their homes (patient : 4 male, 5 female).	Cross-sectional	Interviews and qualitative analysis	No information about validity and reliability testing reported	Most of patients actively made decisions of seeking care 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. They regarded returning home as being important for their recovery and rehabilitation. Patients and families emphasized the importance of professional support which provided encouragement, information, advice, confirmation or feedback.	Small sample size, limited setting, no strategies being used to ensure validity and reliability influenced transferability.
Payne et al. (2009) the UK	To identify patients’ and families’ experiences of acute stroke and preferences for end-of-life care.	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).	Cross-sectional. exploratory study	Semi-structured interview and qualitative analysis	Trustworthiness was established by coding data by independent researchers and reaching agreement, and expert examining data analysis.	Most 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.
Proot et al.’s (2000a) Netherlands	To explore stroke patients’ needs and experiences of autonomy at discharge after rehabilitation.	20 stroke patients from rehabilitation wards of three nursing homes aged between 50 and 85 in Netherlands (12 male, 8 female; mean age 72).	Cross-sectional grounded theory study	Interviews and constant comparative analysis	Data and investigator triangulation, member checking, and peer debriefing to ensure validity.	Patients’ autonomy increased in comparison with those during rehabilitation. Patients reported a variety of facilitating factors (regained abilities and self-confidence, information from professionals, emotional support from family) and inhibiting factors (residual disabilities post stroke, paternalism from professionals, family’s being overprotective) influencing their autonomous decision making.	Only using interview to collect data.
Proot et al. (2000b) Netherlands	To determine facilitating or constraining factors regarding patient autonomy during	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).	Cross-sectional grounded theory study	Interviews and constant comparative analysis	Data and investigator triangulation.	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	Lack of other strategies to ensure validity and reliability.

	rehabilitation from stroke patients' perspectives.					constraining patient autonomy were also discovered (multi-morbidity; lack of information from professionals; over-protect from family).	
Proot et al. (2002) Netherlands	To explore autonomy of stroke patients in rehabilitation wards from the perspectives of health professionals.	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).	Longitudinal grounded theory study	Semi-structured interview and constant comparative analysis	Data and investigator triangulation, member checking, and peer debriefing to ensure validity.	Participants identified process of patients' regaining autonomy and influencing factors. The severity and comprehensiveness of disability post-stroke was 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. Paternalist, overprotective, and preventing families prohibited patients' decision making. 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.	Sample was limited to care providers.
Proot et al. (2007) Netherlands	To understand about autonomy during the whole rehabilitation process from admission to discharge from stroke patients' perspectives.	A consecutive sample of 22stroke 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).	Longitudinal grounded theory study	Interview and constant comparative analysis	Data and investigator triangulation, member checking, and peer debriefing to ensure validity.	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.	Only using interview to collect data.
Rogers and Addington-Hall (2005) the UK	To explore nursing and medical care received by dying stroke patients at the end of their life.	Families and professionals of 22 British patients aged between 58 and 106 years who died in an acute stroke unit (11 male, 11 female).	Prospective study	Non-participant observation and interview and constant comparative analysis	No information about validity and reliability testing reported	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.	Lack of strategies to testing validity and reliability.
Slingsby (2006) Japan	To examine how health professionals in Japan provide rehabilitation therapy to stroke patients.	57 Japanese health professionals (nurses, doctors, clinical psychologists, physiotherapists, occupational therapists, and speech therapists), 48 stroke patients, and	Cross-sectional Grounded theory study	Non-structured and semi-structured interviews, and non-participant	Data triangulation, member checking	Professionals considered a trusting relationship between them and patients and families as the most important factor influencing rehabilitation outcome, and provided rehabilitation using relationship-centred model. This model ignored patient decision making, where professionals prioritized families'	Limited sample or setting influenced transferability of findings.

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)

Author, year of publication, country	Aim(s)	Sample (age, gender, ethnicity) and setting	Design	Data collection and analysis	Rigour	Results	Summary of major limitation
Almborg et al. (2008) Sweden	To explore stroke patients' perceptions of participation in discharge planning and factors related to their perceived participation.	A consecutive sample of 188 Swedish patients with acute stroke from a hospital (mean age 74; male 105, female 83).	Cross-sectional	Face-to-face interview using questionnaire	Instruments were validated.	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.	Exclusion of patient with aphasia or moderate to severe cognitive impairment might influence generalisability of findings.
Bosworth et al. (2004) the US	To examine factors influencing patients' aversion of carotid endarterectomy.	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-econimic data reported).	Prospective cohort study	Secondary analysis of data: patients' demographic, clinical, psychosocial information, and response to question assessing their aversion to carotid endarterectomy and related perceptions	Some instruments used were validated.	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.	Secondary analysis of data; the large majority of male sample.
Chang et al. (2004) Taiwan	To investigate the extent of and factors influencing prehospital delay after acute stroke and delay in help-seeking decisions.	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).	Prospective observational study	Data regarding demographic information and circumstances between onset of stroke and arrival at emergency department were collected using interview and analyzed statistically	No information about validity and reliability testing.	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.	Lack of information about validity and reliability testing.
Christensen and Anderson (1989) the US	To explore spouses' adjustment to stroke with or without aphasia.	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).	Cross-sectional	Self-administered questionnaire survey about demographic information, daily living activities (role change, emotional problems and social adjustment) of spouses, and communication deficits of patients	No information about validity and reliability testing of study instrument.	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.	Non-representative sample and lack of validity and reliability testing, influenced generalisability of findings.
Health Care Commission (2005) the UK	To explore stroke patients' experiences of being in hospital and the care received following	1713 patients from 51 acute hospital trusts (male 940, female 742; 7% aged 16-50, 12% aged 51-60, 23% aged	Cross-sectional	National questionnaire survey	Questionnaire was pilot tested, refined, and	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

	discharge.	61-70, 33% aged 71-80, 25% aged 81 and over; 94% British; respondents living in less socio-economically deprived areas).			with its validity and reliability tested.	reported they were not involved in decision making at all.	others, lower response rate from women, black and minority, living in deprived areas, aged 80+ or 50-. These influenced the responses.
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.	Lack of validity and reliability testing of instrument; Self-selected sample; Low response rate from people living in deprived areas, aged 80+ or 50-, needing help with completing questionnaire or with daily activity, rating care as fair to very poor in 2005 survey. These influenced the responses.
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.	Lack of validity and reliability testing of instrument, using hypothetical scenario, non representative sample influenced generalisability.
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.	Secondary analysis; relying on data from chart to explore informed consent.
Slot and Berge (2009)	To explore patients' preferred content and	75 Norwegian stroke survivors and 75 healthy, age-	Cross-sectional	Questions about content and type of treatment	No detailed information	A majority of participants (93%) wished to receive detailed and precise information on risks and benefits of	Lack of detailed information about

Norway	format of information on treatment effect, and preferred level of involvement in decision making.	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)		information which participants wanted were asked; 3 scales were used to collect data.	about validity and reliability of the study instruments	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.	validity and reliability.
Wellwood et al. (1994) the UK	To understand patients' and carers' perceptions and knowledge of stroke.	A consecutive sample of 65 British patients with acute stroke admitted to a hospital and 80 carers. (patients : 35 male, mean age 69)	Cross-sectional	Semi-structured interview and statistical analysis	Not testing validity and reliability of the study instrument	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.	Validity and reliability testing were not carried out. Missing data or incomplete responses. Generalisability of finding was influenced.
Zhang et al. (2004) China	To explore the effect of a home-based rehabilitation nursing intervention for stroke patients' family carers on their caring ability.	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)	Randomized controlled trial	Self-administered questionnaire survey	No detailed information about testing validity and reliability of the study instrument	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.	Validity and reliability testing were not known.

Appendix 7 Characteristics of Studies on Cultural Influence on Health Care Decision-Making (n=14)

First author, year of publication, country	Aim(s)	Sample (age, gender, ethnicity) and setting	Design	Data collection and analysis	Rigour	Results	Summary of major limitation
Bowman and Singer (2001) Canada	To explore attitudes of Chinese older people towards end-of-life decision making.	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)	Cross-sectional qualitative study	Semi-structured interview and constant comparative analysis	Expert checked the interpretation of data to enhance trustworthiness.	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.	Participants came from one setting, with their attitude being influenced by Canadian health care system.
Cong (2004) China	To examine doctor-patient relationship and informed consent in China.	12 physicians working in different departments, 3 patients, and 3 family members recruited from a hospital in China.	Cross-sectional qualitative study	Interview	Not reported	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.	Strategies for ensuring trustworthiness of data were not known.
Elwyn et al. (2002) Japan	To understand physicians' experiences of cancer disclosure.	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)	Cross-sectional qualitative study	Interview	Member checking,	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.	Rural location increased family participation, and decrease cancer disclosure. Small sample size and all male doctors.
Ganz et al. (2006) Israel	To explore end of life decision making in intensive care unit from a cultural perspective.	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%)	Prospective quantitative study	Patients' types of end-of-life decisions received and demographic information were collected, and analyzed statistically	Not reported	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.	No information about validity and reliability testing
Hattori et al. (2005)	To investigate older patients' preferences	17 hospitalized older patients and 13 patients	Cross-sectional	Semi-structured interview	Member checking,	Most participants identified consideration of families as major factor influencing their wishes for end of life care. They wanted to die at home	Sample selection bias influenced

Japan	and wishes for end of life care.	who went to an outpatient clinic in Japan. (mean age 79.2 age range 67-88, female 23, male 7)	qualitative descriptive study		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.	applicability of findings.
Huang et al. (2003) the US	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.	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).	Cross-sectional quantitative study	Secondary analysis of residents' socio-demographic characteristics, health condition, and disease information	Not reported	Compared with whites, Chinese participants were less likely to make medical decision by themselves, and more likely to depend on families. No differences were found between Chinese, Hispanics, and blacks. There was a lower diagnosis of dementia in Chinese participants on admission to nursing home than other participants. The ethnic differences might be due to family-centered decision making held by Chinese, which was different from white participants' DM model valuing patient autonomy. Under-diagnosis of dementia was because older demented Chinese people and families might not see them as having dementia, so might decide not to seek medical help. Drs with Chinese background might not want to use 'dementia' to name pts' cognitive deficit, due to negative meaning of 'dementia' in Chinese.	Secondary analysis; study setting influenced generalisability; non-representative sample; no validity test; sensitivity and specificity of parameters were influenced.
Humayun et al. (2008) Pakistan	To evaluate the extent to which doctors in Pakistan adhere principles of informed consent, confidentiality and privacy during outpatient consultation.	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 hosptial; mean age 38 range 12-79 in private hosptial)	Cross-sectional quantitative study	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.	Not reported	Obtaining informed consent was observed from only 9.7% of the patients in public hospital and 47.8 % in private hospital. Fewer informed consent obtained from patients reflected the paternalistic model of medical practice in Pakistani culture, where decision was often made only by doctors and patients wanted to follow doctors' decisions. Or decision was made by families and doctors would withhold information from patients based on families' decisions.	No information about validity and reliability testing
Liang (2002) Taiwan	To understand the care practice of caregivers of children with cancer.	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)	Cross-sectional qualitative study	Semi-structured interview	Not reported	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.	No information about trustworthiness of data and finding
Ngo-Metzger et al. (2004) the US	To explore how Asian race or ethnicity influences patients' health care experiences and satisfaction with care.	A stratified sample of 3,205 White-American respondents and 521 Asian-American respondents (Chinese, Filipino, Asian Indian, Japanese, Vietnamese, Korean), who were aged	Cross-sectional national survey, quantitative study	Telephone interview using questionnaire and statistical analysis	Not reported	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	Non-representative sample influenced generalisability. Fewer items in outcome measures decreased

		from 18 to 65 and older living in the continental US. (43% male in both groups)				preferences only when doctors asked them to discuss treatment decisions.	sensitivity. Study design can only suggest associations.
Ruhnke et al. (2000) the US	To compares the attitudes towards ethical decision making and autonomy from physicians and patients in Japan and 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%). Physis 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.	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.	The selection of study settings might influence the generalisability.
Takahashi et al. (2003) Japan	To investigate the association between patients' medical and personal characteristics and decisions of receiving influenza vaccination.	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	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.	Non-respondent bias, recall bias, single setting, and not testing validity and reliability of questionnaire influenced generalisability.
Tang et al. (2006) Taiwan	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.	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.	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.	Convenience sample influenced generalisability.

Yap et al. (2004) Hong Kong	To investigate ethical attitudes of doctors in intensive care unit.	65 doctors working in 11 intensive care units in Hong Kong. (male 40, female 25; 58 doctors under the age of 40)	Cross-sectional quantitative study	Self-administered questionnaire survey and statistical analysis	Not reported	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.	Non-respondent bias influenced generalisability.
Yun et al. (2004) Korea	To understand the attitude of cancer patients and families towards disclosure of terminal illness to patient.	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)	Cross-sectional quantitative study	Self-administered questionnaire survey and statistical analysis	Questionnaire was pilot-tested.	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.	Non-representative sample influenced generalisability.

Appendix 8 Ethical Approval

Ms Yue Wang

PhD student

School of Nursing and Midwifery

University of Sheffield

Dean of School
Professor Anne M Peat

School of Nursing and Midwifery
Samuel Fox House
Northern General Hospital
Herries Road
Sheffield S5 7AU

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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-xxxxxxxx.

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-xxxxxxxx.

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-xxxxxxxx.

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-xxxxxxxx.

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?

The research is carried out by a PhD student, Yue Wang of the University of Sheffield. The interview costs 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, and my email address is: nrp09yw@sheffield.ac.uk.
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 (*or legal representative*)	Date	Signature
____________________________	__________________	____________
Name of person taking consent (*if different from lead researcher*)	Date	Signature

To be signed and dated in presence of the participant

Yue Wang____________________	__________________	____________
Lead Researcher	Date	Signature

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)

Participant No.	Gender	Age	Marital status	Profession	Diagnosis	Stroke incident
1	Male	60	Married	Bank clerk	Ischemic cerebrovascular disease, Diabetes	1
2	Male	65	Married	Retired teacher	Cerebral haemorrhage	1
3	Male	66	Married	Retired engineer	Ischemic cerebrovascular disease, Hypertension	2
4	Male	60	Married	Worker	Cerebral infarction, Diabetes	1
5	Male	73	Widowed	Retired worker	Cerebral haemorrhage, Diabetes	2
6	Male	64	Married	Retired manager of a factory	Ischemic cerebrovascular disease	2
7	Male	61	Single	Engineer	Cerebral infarction	1
8	Male	64	Married	Retired manager of a local government	Cerebral infarction	1
9	Male	67	Married	Retired driver	Cerebral infarction, Diabetes, Hypertension	1
10	Male	61	Married	Manager of a drug manufacturer	Cerebral infarction, Diabetes	2
11	Male	65	Divorced	Retired engineer	Cerebral haemorrhage	1
12	Female	74	Widowed	Retired worker	Ischemic cerebrovascular disease, Diabetes	2
13	Male	63	Married	Retired worker	Cerebral infarction, Diabetes, Hypertension	2

14	Male	80	Married	Retired worker	Cerebral infarction	3
15	Female	65	Married	Retired hairdresser	Ischemic cerebrovascular disease	1
16	Female	67	Married	Retired engineer	Cerebral haemorrhage	1
17	Male	61	Married	Engineer	Cerebral infarction	1
18	Female	60	Married	Teacher	Ischemic cerebrovascular disease	1
19	Female	70	Married	Retired worker	Cerebral infarction	2

Appendix 14 Socio-demographic Characteristics of the Participants (carers, n=28)

Participant No.	Gender	Age	Relationship of participant to patient	Profession
1	Male	52	Son	Worker
2	Male	48	Son	Teacher
3	Male	77	Husband	Retired warehouse manager
4	Female	57	Daughter	Teacher
5	Female	58	Daughter	Accountant
6	Female	52	Daughter	Worker
7	Male	55	Son	Trade union steward
8	Female	40	Daughter	Secretary
9	Female	62	Daughter	Retired engineer
10	Female	62	Wife	Retired worker
11	Male	50	Son	Worker
12	Female	44	Daughter	Worker
13	Male	56	Son	Teacher
14	Male	50	Son	Manager
15	Female	61	Wife	Retired worker
16	Female	55	Daughter	Worker
17	Male	70	Husband	Retired worker
18	Male	44	Son-in-law	Hotel manager
19	Female	52	Daughter	Accountant
20	Female	61	Wife	Farmer
21	Female	33	Daughter	Worker
22	Female	67	Wife	Retired teacher
23	Female	45	Daughter	Worker
24	Female	58	Wife	Manager
25	Female	54	Daughter	Worker
26	Male	51	Son	Engineer
27	Male	63	Husband	Retired teacher
28	Female	45	Daughter	Saleswoman

Appendix 15 Socio-demographic Characteristics of the Participants (professionals, n=25)

Participant No.	Participant interviewed	Gender	Age	Years of experience	Education level	Clinical specialty
1	Doctor	Female	37	12	Master	Neurology
2	Doctor	Female	35	9	Master	Neurology
3	Doctor	Female	36	13	MD	Neurology
4	Doctor	Female	31	6	Master	Neurology
5	Doctor	Female	35	12	MD	Neurology
6	Doctor	Female	45	20	Master	Neurology
7	Doctor	Male	36	6	Master	Neurology
8	Doctor	Female	28	1	Master	Neurology
9	Doctor	Male	29	1	MD	Neurology
10	Doctor	Male	35	7	Master	Neurology
11	Doctor	Male	30	4	Master	Neurology
12	Doctor	Female	34	7	Master	Neurology
13	Doctor	Female	39	16	Master	Neurology
14	Doctor	Female	37	14	Master	Neurology
15	Doctor	Male	46	20	Master	Digestive disease
16	Nurse	Female	38	18	Bachelor	Neurological nursing
17	Nurse	Female	27	5	Associate	Neurological nursing
18	Nurse	Female	26	4	Associate	Neurological nursing
19	Nurse	Female	25	3	Associate	Neurological nursing
20	Nurse	Female	36	15	Bachelor	Neurological nursing
21	Nurse	Female	39	17	Bachelor	Neurological nursing
22	Nurse	Female	40	20	Diploma	Neurological nursing
23	Physiotherapist	Male	24	1	Bachelor	Physiotherapy
24	Physiotherapist	Female	35	3	Bachelor	Physiotherapy
25	Acupuncturist	Female	41	17	Bachelor	Acupuncture (TCM)

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 initiatively 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%)

<u>Decision-making during ward round</u>

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

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

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.	Patient’s disease history Patient’s past treatment experience
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.	Family history Understanding gained through past life experience (source of knowledge)
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.	Deciding how to help patient take medication Deciding how to prevent bed sore Making decision relevant to psychological care
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	Deciding how to help patient take medication Patient’s disease history Patient’s past treatment experience Past life experience of caring for patient (giving medication)

53	small amount of decoction.	
54	Then when delivering the concentrated decoction, because she had normal sense of	Past life experience of caring for patient (giving
55	taste, so I used the fruit juice to help her take the medication, for example, giving	medication)
56	one spoon of pineapple juice, then giving one spoon of medication, and after that	
57	giving another spoon of pineapple juice, or sometimes I used orange juice to help	
58	successfully administer medication to her. I think because my mother still had	
59	normal chewing and swallowing functions, but just didn’t had very normal	
60	consciousness level, so although her sense of taste allowed her to know that she was	
61	taking bitter medication, she still could successfully take the oral medication with	
62	the fruit juices.	
63	During the current hospital stay, yesterday we found it very difficult for her to take a	
64	certain powdered medication, so we had to help her take it with her meals. Today we	Deciding how to help patient take medication
65	ask the doctor whether we can deliver this medication with yogurt, and the doctor	Asking doctor
66	says that using yogurt to give medication is not good for patient because the yogurt	Doctor answering/explaining
67	can influence the pH level of the drug. So now we need to figure out how we help	Trial and error for medication
68	her take the medication at noon today, for example, taking the medication with	
69	lunch, so I have to try my best to successfully give the medication to my mother.	
70	I am also thinking that, for example, whether we can give the medication with water	Deciding how to help patient take medication
71	in which we add some honey to improve the taste, but you know, since her blood	Quite complex reasoning
72	sugar level is a bit higher than normal, so we need to make sure that the method	Thinking holistically before making decision
73	which we choose doesn’t have negative impact on her blood sugar level.	
74	Daughter: I think taking medication with meal is better than taking medication with	
75	yogurt for the patient’s treatment and recovery.	
76	YW: Plain boiled water is more suitable, according to the doctor.	
77	Daughter: But we can do nothing about it. I know clearly that the patient will have	
78	better treatment effect if she takes medication with plain boiled water rather than	
79	with food, but what can I do, it is almost impossible for her to take the medication	
80	with water. I think at least she can benefit from the treatment effect of the	Choosing the least worst option
81	medication to a certain degree if she takes it with her meal.	

82	Anyway, I think, there are two difficulties of caring for this kind of patients, one is	
83	giving medication, and the other one is giving them water to drink. You know, when	
84	caring for my father who once also had cerebral infarction, I asked him to drink	Past life experience of caring for other family
85	water when he sat up on the bed, but he always refused. And finally, since I just	member (with similar condition)
86	could do nothing about it, so I had to allow him to lie flat in the bed and then gave	Choosing the least worst option
87	him water. And I thought, it’s impossible for him to get enough water only through	
88	receiving IV infusion, right, given the large amount of water which he needed.	
89	YW: Right. It’s impossible for the patient to always get water only by receiving IV	
90	infusion.	
91	Daughter: in addition, he had hemiplegia, and was also unable to suck water	
92	properly with drinking straw. So, finally, after trying all the methods to solve the	Making decision by trial and error
93	problem, I decided that I allowed him to lie in the bed, then I gave a very small	Solving problem
94	amount of water each time, in case that he suffered from coughing and choking.	
95	Especially, at the later stage of his stroke, we also allowed him to lie in the bed and	Past life experience of caring for other family
96	then helped him eat food, because it’s difficult for him to sit up and then eat and	member (with similar condition)
97	swallow the food. And we used the similar method to deliver the oral medication to	
98	him at that time.	
99	YW: These are important experiences.	
100	Daughter: Yes. Unlike us, he was unable to finish these activities normally. But I	
101	think it is easier for us to care for my mother than to care for my father, since she	
102	doesn’t have a very serious stroke.	
103	Son: The second important issue of caring for patients with neurological disease is to	Making decision relevant to bed sore prevention
104	prevent bed sores, because these types of patients generally all need to stay in bed	
105	due to their severe condition, and are very likely to develop bed sores or even	
106	infections. So we all work very hard and actively carry out various caring activities,	Providing nursing care
107	such as applying hot compress, washing the patient to keep her skin clean, turning	
108	the patient frequently and assisting her to pass urine and stool. We have a bed at	
109	home whose function is very much similar to that of a special toilet seat, and is	
110	particularly useful and convenient for her to pass urine and stool. So we all try to	Trying to provide best care

111	provide the best possible care to my mother.	
112	The last important point is the recovery of her psychological condition, and I think	Making decision relevant to psychological care
113	we have figured out a so-called ‘psychological treatment’ and plan to deliver it to my	Foreseeing future rehabilitation needs
114	mother after she discharges from the hospital. What is the psychological treatment? I	Making future care plan or choice
115	find that our parents are both very old, and have a very common characteristic	
116	related to their memory, which is that, older people remember events of long ago	
117	better than recent events.	
118	Therefore, since my mother is very interested in singing, so I think we will give	Making future care plan at home
119	singing therapy to her. She can sing a lot of different old songs, and we have various	Life history
120	old songs CD or DVD at home. And I know that she may not be able to successfully	Anticipating rehabilitation and future recovery
121	sing the full song at the very beginning after discharge, but I believe that her	
122	condition may get improved gradually, and she may be able to sing the whole song	
123	after practicing for a period of time, and this will indicate that her brain function has	
124	recovered.	
125	YW: You can know how well her brain function has recovered.	
126	Son: Right. For example, if she can sing two sentences in a song today, and three	Monitoring recovery
127	sentences tomorrow, and four the day after tomorrow, so this means that my strategy	
128	is helping her gradually recover from her disease, or this is motivating, how to say,	
129	maybe I can say, this is activating her brain cells? In addition, I think this strategy	Thinking holistically
130	can be helpful for her overall or holistic recovery.	
131	Another method to facilitate her recovery is to go out for sightseeing. I believe that if	
132	you can look at and enjoy those beautiful scenes, you will have a very happy mood,	Maintaining happy mood (harmony)
133	especially when you always live in an urban city and you feel like you are under a	
134	lot of pressure. So I think I will take her out for sightseeing, take her to the	Making future care plan at home
135	countryside to broaden her views, and meanwhile, she can also enjoy the fresh air. I	
136	think, for the purpose of her good recovery, going out is much better than staying at	
137	home.	
138	YW: You know a lot about caring for older patient with stroke, would you tell me	
139	how you gain these experiences?	

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.	Seeing love as motivation of caring for patient Loving relationship between family members
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.	Past life experience of caring for patient Taking long time to establish loving relationship
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.	Seeing love as motivation of caring for patient Solving problem Deciding how to help patient take medication Making decision based on past life experience (source of knowledge) Making decision by trial and error Meeting individual/particular needs
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	Considering patient’s individual condition Adapting information (to make it suitable for patient’s level of understanding) Tailoring information (to meet patient’s particular

169	accordingly.	needs)
170	YW: You do all these things because you love your mother.	
171	Son: Yes, three of us all love her very much, and always encourage her to actively	Loving relationship between family members
172	receive treatment and fight against her disease. I think we need to give her more	Making decision relevant to psychological
173	encouragement rather than criticism or blame.	support
174	The second important thing is to get information or knowledge about caring for the	Getting care related information/knowledge
175	patient. I feel that I have become half a doctor after I spend such a long time looking	Seeing himself as an expert carer, drawing on
176	after my mother, for example, caring for her when she was sick in the past as well as	expertise based on long term experience of caring
177	during her current hospitalisation. A long time ago when people didn't have access to	for patient (source of knowledge)
178	the internet, I very much would like to read books to gain more medical knowledge	Getting information from book (source of
179	or information. After I gain lots of knowledge, when I communicate with health	knowledge)
180	professionals, doctors, there will not be a huge gap between both of us. Otherwise, if	Having equality with professionals
181	there is a huge knowledge gap between you both, I am sure that they will not be	Gulf in knowledge between professioanls and lay
182	willing to talk with you.	people influencing communication
183	And more importantly, because it is you who spend much longer time staying with	Seeing himself as an expert carer, drawing on
184	and caring for your patient at her bedside than the doctor, so you can provide all the	expertise based on long term experience of caring
185	information about patient’s condition to the doctor, right?	for patient (source of knowledge)
186	YW: Yes.	Providing information
187	Son: Although I don’t know which treatment should be given to the patient to solve	
188	her problem, telling doctor the patient’s condition can provide him or her more	Providing information for making diagnosis
189	information which will be taken into consideration by him or her, or be used as	Providing information for making treatment plan
190	evidence to make accurate diagnosis. Again, for example, after she takes medication,	Providing information for assessing recovery
191	what’s the change of her condition, what’s her treatment effect, I will give this	
192	information to doctors. I think by doing so, I can establish an interaction with health	Building relationship through interaction
193	professionals, which are good and helpful for patient’s treatment.	
194	I think as a family carer, I need to closely work together with health professionals,	Closely working together as one
195	we are like one person, such a kind of relationship will be extremely beneficial for	
196	patient’s treatment. So I think I need to establish an interaction with doctors and	Building relationship through interaction
197	nurses. In addition, I will also timely tell health professionals about the good	Relationship building as a strategy

198	progress which they have made in order to improve or enhance their confidence, for	Providing positive information
199	example, timely telling them the positive change or improvement of patient’s	
200	condition, or the effectiveness of treatment.	
201	So that’s why I would say the interaction between carers and health professionals is	Building relationship through interaction
202	very important, and both of us need to work closely with each other, we are just like	Closely working together as one
203	one person, and we blend into one entity. It’s totally not like a kind of relationship in	Having a non-commercial relationship
204	which I come here to give money to you, and you provide treatment to me. Health	
205	professionals and carers both share a common goal which is to provide effective	Sharing a common goal
206	treatment for patient and solve his or her problem, or cure his or her disease, we both	Closely working together as one
207	have the same purpose, so we need to work together and integrate into one entity.	Having the same purpose
208	YW: Just now you said that you could get information or knowledge of caring for	Maintaining harmony
209	the patient from the internet, do you have any other sources which you can search to	
210	get related information?	
211	Son: I have read some books which introduce the related information. I feel like I	Getting information from book (source of
212	consider caring for the patient as a major research topic, this is an important research	knowledge), treating patient care as a research
213	topic which I always think about in my mind. So if I have some questions to ask, I	topic
214	will try to get the answer or information, for example, from the internet, which is	Asking question, getting information from
215	extremely fast, so I can quickly get the information which I need.	internet
216	YW: Right, very convenient.	
217	Son: Yes, if I have something which I don’t understand, or if I have got questions, I	Getting information from internet
218	can immediately search the internet, and then quickly get related information.	
219	YW: Next, I am wondering, in your mother’s current hospitalisation, do you mainly	
220	come here to look after her?	
221	Son: Yes, over the last couple of days, both my younger brother and sister have been	
222	very busy, and therefore don’t have enough time to come here to look after my	
223	mother, so I always stay in the hospital and take care of her. I think, as the oldest	Staying with and caring for patient, the oldest
224	child in the family, I need to take responsibility for everything that happens in our	child, taking family responsibility
225	family, and in order to help my mother get effective treatment and good recovery,	
226	and I need to try my best to overcome all the difficulties which we may encounter	Problem solving

during her hospital stay.	
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.	Hiring a helper at home, instructing helper Deciding to live with patient at home
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.	Giving explanation Cooperating with doctors, accepting examinations, cost is no object
YW: Does your mother have health insurance?	
Son: Yes, she has health insurance.	Having 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.	Accepting all examinations without hesitation Cost is no object
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,	Importance/benefit of proving information Negative impact of lack of information

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.	Cost is no object
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.	Sharing care with family Having a discussion within family
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 10days.	Being required to give consent Disagreeing with doctor Giving explanation
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.	Giving consent, cooperating with doctor Sharing a common goal, in patient's best interest Same goal different role
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	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.	Cost is no object Goal for treatment
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.	Accepting nurses’ advice
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.	Making care related decision, choosing hand for IV therapy, leaving decision up to nurses Encouraging rather than criticising (creating or maintaining harmony)
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 our best 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.	Encouraging as strategy for relationship building Establishing good relationship (creating or maintaining harmony), cooperating with nurses Thinking realistically about nurses’ performance Establishing rather than destroying good relationship (creating or maintaining rather than destroying harmony)
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	Being an integrated entity
315	an integrated entity, one person, we work closely together as a holistic entity, rather	Working together rather than separately/alone
316	than a separate individual or party, I mean, not like, you belong to this party, but the	
317	patient and I belong to that party, no like that. Our relationship is actually like, we	
318	are a unified entity, although we may play different roles or look at things from	Being an integrated entity, different roles,
319	different perspectives.	different perspectives
320	YW: You once mentioned that you both share the common goal.	
321	Son: Yes, we have the same goal, although we play different roles, we’ve got the	Same goal different role
322	same purpose which is to cure the patient’s disease.	
323	I think after the patient is admitted, we need to start to closely work with health	Working together with professionals
324	professionals as soon as possible by using two strategies. Firstly, you need to rely on	Relying on rather than disagreeing with
325	them rather than disagree with or get into conflict with them. You also need to	professionals
326	respect them, really follow their advices and conscientiously act out those advices.	Respecting professionals, following their advice
327	Secondly, you need to quickly improve your medical knowledge level, and	Getting care related information (source of
328	immediately search different sources to get necessary information or knowledge.	knowledge), searching different sources,
329	You need to particularly pay attention to the extent to which you consult health	Asking professional questions
330	professionals when you have questions or something you don’t understand. For	
331	example, after they give you the explanation of a certain issue, don’t immediately	Giving explanation
332	ask them once again if you are still unclear about some of their explanation, and	Not to question professionals unless necessary
333	don’t repeatedly bother them with too many questions again and again, as they are	Establishing rather than destroying good
334	very busy in their work and don’t have enough time to answer your questions.	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 2^{nd} 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 (①cost 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 (①the patient chooses to go to the famous hospital with high reputation of good quality service and professional expertise; ②good reputation can help establish patient's trust towards doctor and hospital.)

Working experience (job skill, patients' profession) (①the patient's understanding of hospital reputation gained from his working experience in a drug manufacturer helps him make choice among hospitals; ②experience 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:

<u>‘Sharing’:</u>

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.

<u>‘Seeking’:</u>

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.

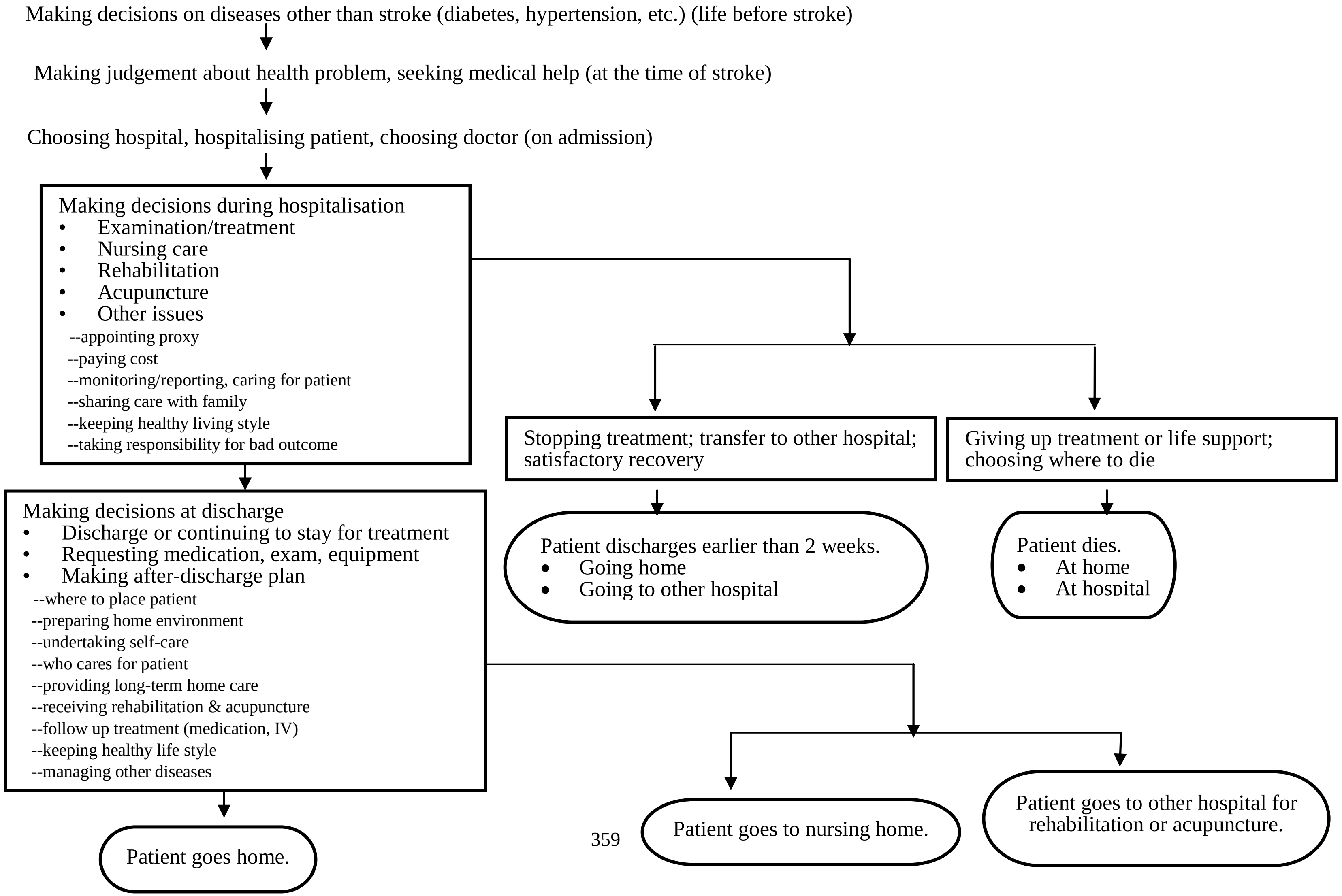
I believe that there should be some religious beliefs-related factors which exert the above influences on people’s decision-making behaviours.

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



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 <u>seeking</u> 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.
    - o <u>Watching/comparing</u> 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.
    - o Sometimes, the patient and carers used <u>checking</u> 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.