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# **Working with Family Carers Following Acute Stroke in China:**

## **‘Hiding’ as a Barrier to Partnerships Between Older People, Family Carers and Professionals**

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# Outline of Presentation



- Background of the study
  - The rationale for the study
  - Major findings in the existing literature
- Methodology
  - Study design, data collection and analysis
- Findings
  - 'Hiding' - the barrier to partnership working after acute stroke
- Discussion
  - The role of traditional cultural values in China and the threats they face
  - The relevance of 'partnership working' to the hiding process
- Conclusions
  - Implications for the future of 'partnership working' in culturally diverse context

# Objectives

- To explore the role of family carers in health care decision making in China
- To identify the barriers to partnership working after acute stroke, especially the process of 'hiding'
- To discuss the role of traditional cultural values in countries such as China and the threats they face in a rapidly changing social context
- To consider the implications of such changes for the future of notion such as partnership working in culturally diverse contexts



## Outcomes



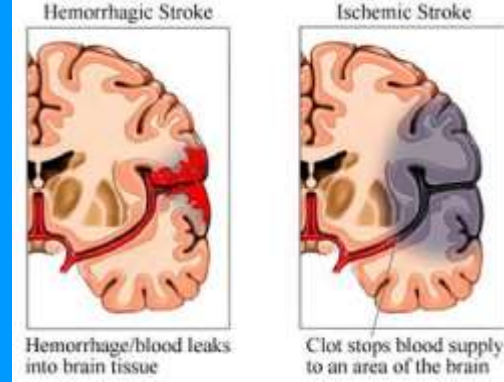
- Those attending this session should, as a consequence:
  - Be able to take a more critically informed view of the relevance of 'western' concepts such as partnership working in other cultural contexts
  - Have a better awareness of the largely implicit influence of long-standing cultural values on real life situations for older people and family carers in China
  - Reflect on how professionals can both be made aware of such influences and what they might do to ensure better informed interactions with family carers in the future

# Background of the Study

- The rationale for the study
- Major findings in the existing literature



## The Rationale for the Study



- Stroke-a major public health concern in China (Ministry of Health, 2013)
  - Significant mortality, long-term morbidity, physical, psychosocial problems, decreased quality of life (Kahraman and Jones, 2009)
  - The third and the second most common cause of death among urban and rural residents respectively in 2012 (Ministry of Health, 2013)
  - Older patients with stroke and family carers have to make major life decisions in a short time (Brereton and Nolan, 2003)

## The Rationale for the Study



- The concept of partnership working in a Western context
  - The stroke survivor's major role in decision-making (Hoffmann and Cochrane , 2009)
  - Wider involvement of older people in making care decisions which are perceived as 'difficult'
  - Very little ethical debate or empirical work on patient participation in health care decision-making in China

## Major Findings in the Existing Literature

- Preliminary Findings from Literature Review
  - The processes of making decisions: E.g., seeking
  - Influencing factors
    - E.g., age, gender, educational level, condition/severity of illness, the extent to which patients & carers are well informed about their condition and supported to make decisions, the degree of trust that they have in health and social care professionals.
  - The role of Eastern culture in health care decision-making
    - E.g., the role of family.





## Aim and Objectives of the Study



- Aim

To explore how decision-making take place between older people with stroke, their family carers and professionals in an acute care context in China.

- Objectives

- ❖ Explore perceptions and experiences of making decisions.
- ❖ Identify types of decisions being made.
- ❖ Examine factors influencing decision making and patient involvement.
- ❖ Investigate knowledge needed to inform decision-making.

# Methodology



- Study design: constructivist grounded theory
- Data collection
  - ❖ Purposive sampling and theoretical sampling
  - ❖ Semi-structured interview with:
    - Older patients with stroke
    - Family carers
    - Professionals
  - ❖ Participatory observation
  - ❖ Documents
- Data analysis
  - ❖ Constant comparative analysis
  - ❖ Co-construction of the findings



## Findings of the Study

- Keeping the peace
- Hiding

# The Core Category of Keeping the Peace

## Keeping the peace

- Interpersonal level:
  - ❖ Keeping the peace in relationships
    - Inter-professional relationships
    - Inter-familial relationships
    - Relationships between professionals, patients, and carers
    - Relationships between patients/carers sharing the same ward
- Personal level:
  - ❖ Keeping the peace of mind (happy mood)



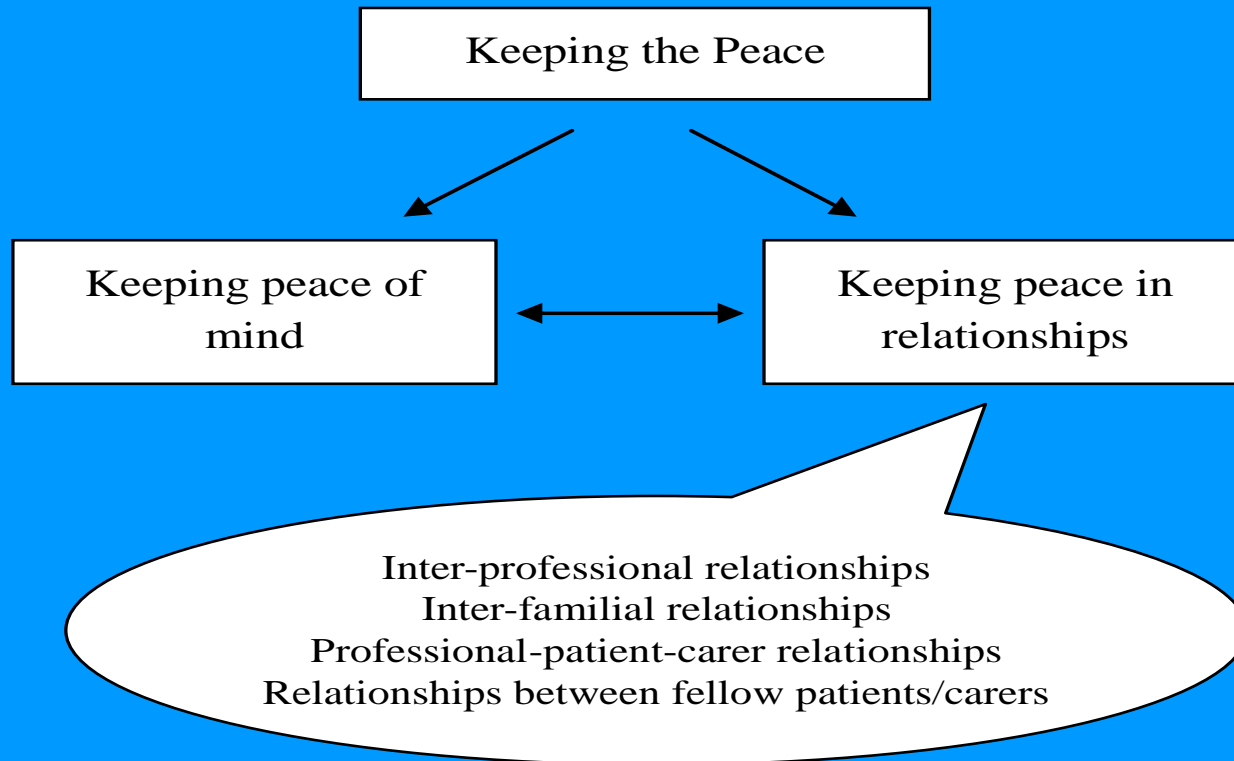


Figure 1 The core category of keeping the peace

# The Core Category of Making Decisions

In order to make the best use of information and effectively make decision, patients, carers and professionals used an extensive range of processes:

- Seeking
- Sharing
- Hiding
  - ❖ Temporary hiding
  - ❖ Permanent hiding
  - ❖ Tailoring to hide



## Temporary Hiding

- Patient hiding information from carer:
  - ❖ Hiding the truth about their disease and/or hospital treatment
- Carer hiding information from carer:
  - ❖ Hiding information about hospitalization



# Permanent Hiding



- Professional/carer:
  - ❖ Either downplaying or strictly keeping bad news or negative information (e.g., poor diagnosis/prognosis, risks, financial difficulties) from patients in order to keep patient's peace of mind.
- Carer:
  - ❖ Hiding negative information from patient's older spouse (e.g., patient's treatment involving risks).
  - ❖ Hiding information about patient's hospitalisation from other relatives in order to avoid bothering them to visit/look after patient.
  - ❖ Hiding information about financial difficulties from doctors.
- Patient:
  - ❖ Hiding prior medical history/behaviour of stopping medication from doctors



## Tailoring to Hide

Professional selectively tailoring information based on:

- The perceived trustworthiness of carers/patients
- The expected outcome/consequence of a choice



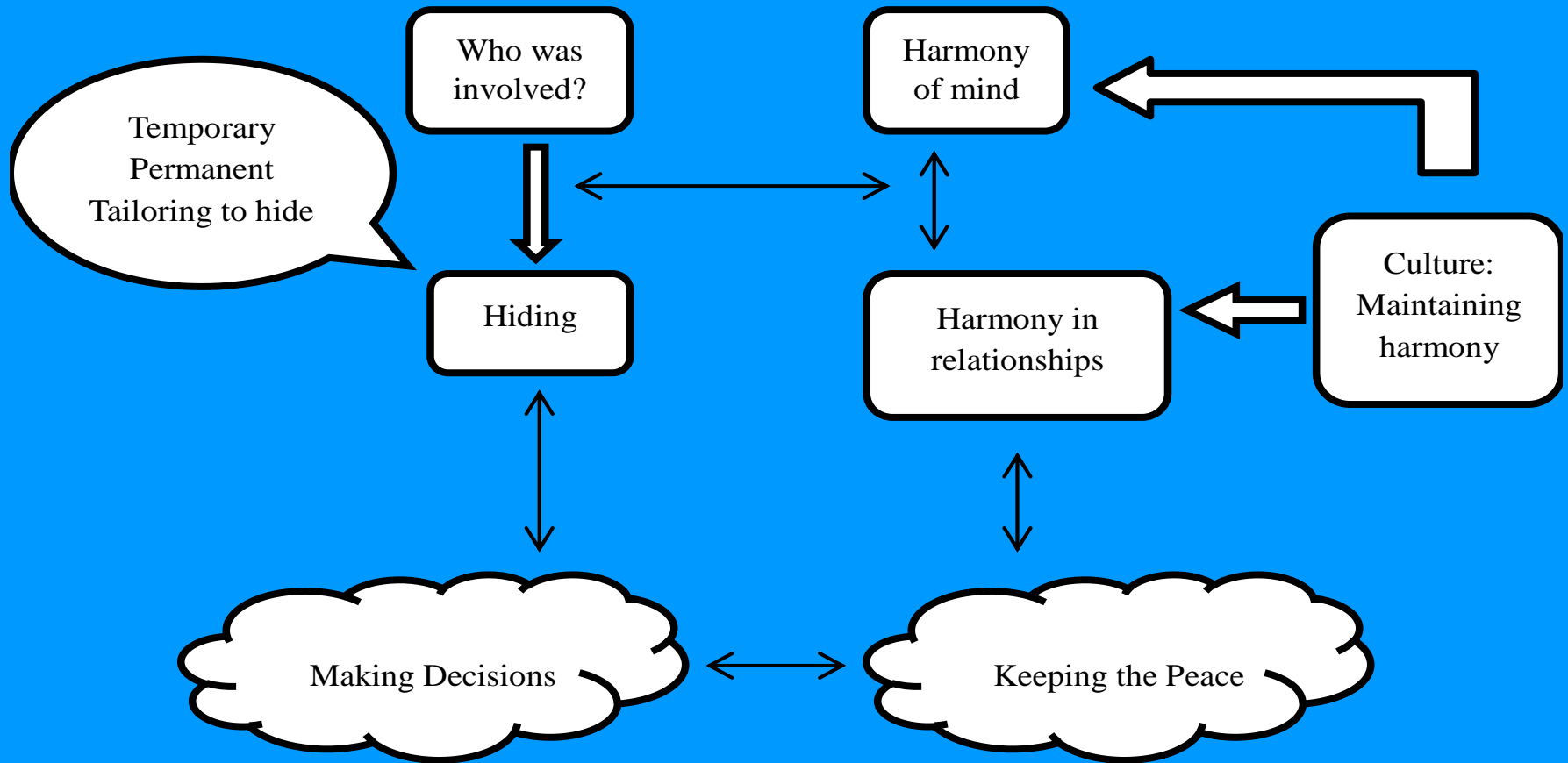
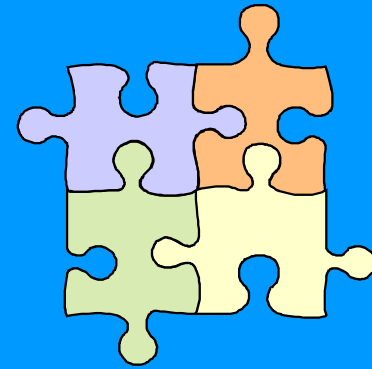


Figure 2 Dynamics between the two core categories and other factors



## Dynamics between Core Categories

- Making decision is the focus throughout patient journey and significantly influenced by 'hiding'.
- Keeping the peace is an equally important motivation for 'hiding' and is underpinned by the traditional Chinese cultural value of 'maintaining harmony'.
- 'Keeping the peace' comprised maintaining 'peace of mind' for the patient and also maintaining harmony in interpersonal relationships.

# Discussion

- The role of traditional cultural values in China
  - The ideal of maintaining harmony exerts a significant influence on decision-making in acute care contexts.

**the desire of all parties (carers & profs.)  
to adhere to traditional Chinese cultural value  
of maintaining harmony**

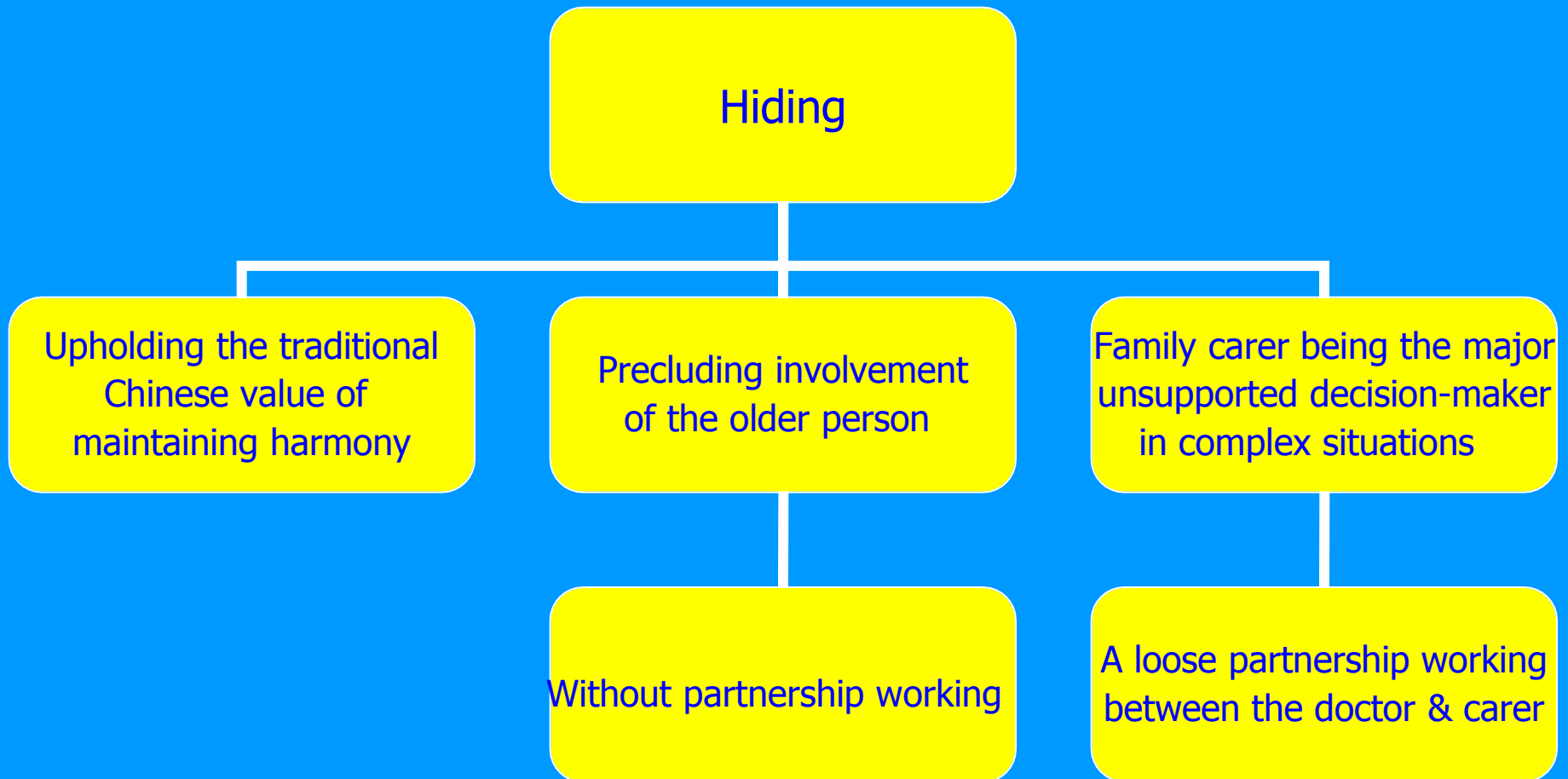
**using 'hiding' behaviours to 'keep the peace'**

**effectively precluding older patients from  
full and active involvement in  
what were perceived to be 'difficult' decisions**

- The threats that traditional cultural values in China face
  - China is rapidly becoming more Westernised.
  - Traditional culture values are being eroded (Knight, 2000).

# Discussion

- The relevance of 'partnership working' to the hiding process





## Conclusions

- Implications for the future of 'partnership working' in culturally diverse context
  - Health professionals need to be aware of/identify
    - ◆ The traditional role of patient and carer in health care decision-making in a particular cultural context
    - ◆ The new role of patient and carer in health care decision-making
    - ◆ The barriers to partnership working in health care decision-making
    - ◆ Challenges which they face in a changing social context
  - Health professionals need to
    - ◆ Evaluate patients' and carers' desires and expectations
    - ◆ Work with them in 'partnership' or facilitate their participation in health care decision making in a culturally acceptable way.

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# Many Thanks

## Welcome

Questions  
Comments  
Suggestions

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