Working with Family Carers Following Acute Stroke in China:

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

Yue Wang, PhD, Associate Professor, School of Nursing, Tianjin Medical University, China
Mike Nolan, PhD, Professor, School of Nursing and Midwifery, University of Sheffield, the UK
Elizabeth Hanson, PhD, Professor, Department of Health and Caring Sciences, Linnaeus University, Sweden

4th September 2015
Sweden
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
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 decisions, 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

- Making Decisions
- Keeping the Peace

Who was involved?

Harmony of mind

Hiding

Harmony in relationships

Culture: Maintaining harmony

Temporary
Permanent
Tailoring to hide

Harmony of mind

Making Decisions

Keeping the Peace

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

- Upholding the traditional Chinese value of maintaining harmony
- Precluding involvement of the older person
- Without partnership working
- Family carer being the major unsupported decision-maker in complex situations
- A loose partnership working between the doctor & carer
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.
List of key references/resources

List of key references/resources


Many Thanks

Welcome

Questions

Comments

Suggestions

Email: yuewangn@163.com