

End of life care: experiences and attitudes of white indigenous and Chinese older people living in the UK.

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Background

- ▶ Specialist palliative care services are not accessed by Chinese and other ethnic minority groups according to their needs.
- ▶ All older people are disadvantaged in relation to palliative and end of life care.
- ▶ Little known about how the experiences and attitudes of older adults from white and ethnic minority groups compare.

Aims

- ▶ This paper presents a comparison of findings from two linked studies of indigenous white (n=77) and Chinese (n=92) older adults living in the UK.
- ▶ Perceptions and knowledge of palliative and hospice care.
- ▶ Views about dying at home and the 'good death'

Chinese communities in the UK

- ▶ 247,403 people of Chinese origin in the UK, **0.4% of the total population** and **5.3% of all black and minority ethnic people in the UK.**
- ▶ Rich and complex cultural traditions.
- ▶ **Origins** – Mainland China, Hong Kong, South East Asia, Malaysia.
- ▶ **Language** – one written language, many spoken dialects.
- ▶ **Employment and settlement.**

Method

- ▶ **Study 1:** indigenous 'white' elders living in Sheffield, 2001-3 (n=77; age range: 55-90; m = 25 f= 52).
- ▶ **Study 2:** older Chinese people living in Sheffield and Manchester, 2003-5 (n= 92, age range: 50-90; m = 26 f= 66).
- ▶ **Research ethics committee review.**

Both studies used the same design

- ▶ **Qualitative** in 2 phases
- ▶ Purposive and snowballing **sampling** methods
- ▶ Links made to community groups and GPs
- ▶ **Phase 1** –focus groups¹
- ▶ **Phase 2** – semi-structured interviews ²
- ▶ Qualitative **analysis** using constant comparison aided by NVIVO.

1. Study 1: 32 participants in 6 groups; Study 2: 46 participants in 7 groups.

2. Study 1: 39 interviews; Study 2: 46 interviews (37 in Manchester and 9 in Sheffield).

The role of palliative and hospice care

- ▶ Both groups linked 'hospice' to 'death'
- ▶ White elders talked about hospice in idealised terms: *'wonderful' or 'special' staff; the ability to transform death from a bad experience to a good one, and the provision of care, comfort and 'ease'.*
- ▶ Chinese elders saw hospices as **'inauspicious'**: *undermining readiness to prepare for the completion of life tasks; demonstrating that one had become a 'burden' to family; a 'last resort' for care.*

Dying at home

- ▶ **White elders saw home as the ideal place of care** but saw problems: *worries about being a 'burden' to family; concerns about the caring skills of family carers; risks of inadequate symptom relief.*
- ▶ **Chinese elders had similar concerns and strongly preferred hospital care:** *burden; provision of nursing care; worries about 'contamination' and 'contagion' of the home:*

They should be in hospital, of course! You wouldn't bother to stay at home; you wouldn't want to wait till the last... (Man, interview 15)

And if you die in the house, you know, the house is not a good house any more. When you've had an accident in the car, no Chinese would buy a car that had been in an accident. (Woman, interview 27)

[It] would cast this shadow on you; and they say if you die at home it would make the home 'dirty' ... (Woman, interview 25).

Beliefs about the 'good' death

- ▶ Both groups placed primary importance of **pain relief, family presence and comfort** during dying.
- ▶ **Dying 'cleanly'** and **not burdening** others (particularly one's adult children) was of key importance to both groups.
- ▶ Opportunities to maintain a sense of **personal identity** was crucial to both groups.
- ▶ **Chinese elders** talked about '**dying with the eyes closed**'.
- ▶ **White elders** emphasised death at the '**right time**'.

Dying with the eyes closed: Chinese elders' views

- ▶ Coherence or integrity of family relations
- ▶ Knowing that one has children who are married; knowing that one has grandchildren.
- ▶ Having family at the bedside of the dying person. The timing of death therefore has to be managed to allow this to occur.
- ▶ Finished business: in which ambitions and life goals are complete.
- ▶ Ideally if death occurs with the eyes closed, then the body is in a peaceful state and that the spirit can 'fly' to the sky smoothly.

"With regards to 'has died with the eyes closed', this is.....well, he knew he was going to die and had made all the arrangements and all his children were married with families and had jobs." (Woman, interview 31)

Death at the 'right time': white elders' views

- For some, this was pre ordained by God and may not fit with one's own preference:

If He says you stay, you stay: if He says you go, you go. I mean, particularly when it's young people, you know, you think why? You start saying why? ... You don't answer, you don't know how to answer those questions, but there must be a reason, mustn't there?

- For others, this was a matter of personal choice, supported by technologies or devices of end of life care (such as a 'living will'):

I have ... I have ... I've written mine firmly and had it attested right by the solicitor that I do not want to be kept alive by artificial means.

Conclusion and implications for service provision

- ▶ Older white and Chinese adults living in the UK have some similar concerns/ attitudes to end of life care, with some distinct differences in relation to perceptions of 'hospice'.
- ▶ Care preferences are not culturally 'scripted', but reflect practical, moral *and* cultural concerns.
- ▶ These data shed critical light on the policy of increasing death at home.
- ▶ Service provision needs to take account of concerns about informal care among older adults from diverse ethnic backgrounds.