How is Palliative Care Organised for Older Adults With Dementia Who Are Living and Dying in Residential Care Homes in the West of Scotland?: An Original Study Using the Principles of Institutional Ethnography.

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Background

There is one classification of "care home" in Scotland; but two levels of service provision:

❖ Nursing Care Homes and,

❖ Residential Care Homes.

Residents in both settings are increasingly frail and disabled. Many are living and dying with dementia. People with end-stage dementia can experience a range of difficult symptoms in the last six months of life. For example, confusion, pain, incontinence and loss of appetite.
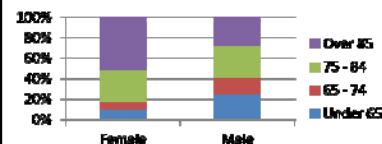
Recent drives to improve palliative care in Scotland promote the use of palliative frameworks and tools such as the Gold Standards Framework and the Liverpool Care Pathway. These are healthcare documents, designed **for** healthcare professionals **by** healthcare professionals. This creates the potential to create an imbalance between nursing care homes (with on-site healthcare staff) and residential care homes (without on-site healthcare staff).

Research is needed to investigate how palliative care is organised for older adults with dementia who are living and dying with dementia in residential care homes in Scotland.
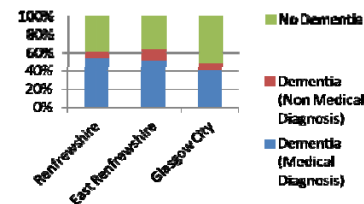
Demographics

(2010 Care Home Census)

Age and Gender of Residents (Scotland)

Over 85
75 - 84
65 - 74
Under 65

Living With/Without Dementia (Council Areas)

No Dementia

Dementia (Non Medical Diagnosis)

Dementia (Medical Diagnosis)

Care Providers (Scotland)

Voluntary

Private

Local Authority/NHS
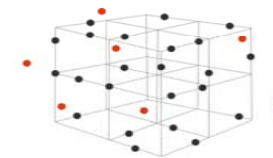
Institutional Ethnography (IE)

Dorothy E. Smith uses the metaphor of a dot-to-dot cube to describe IE, a "sociology for people".

Smith states that people and events are connected through powerful, but invisible, social relations which structure their everyday lives.

Although there is no suggestion of malicious intent, these relations are not necessarily impartial or fair.

IE gathers information on actions, talk and texts. It then "joins the dots", to make a map which demonstrates how things are organised to happen as they do.

Ethical approval for this study has been granted. Data collection will begin by December 2011.

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