



# Frontline direct care workers experiences of providing domiciliary care towards the end of life: A systematic literature review and narrative synthesis Sean Hughes, Vivien Holt, Nancy Preston International Observatory on End of Life Care, Lancaster University, UK

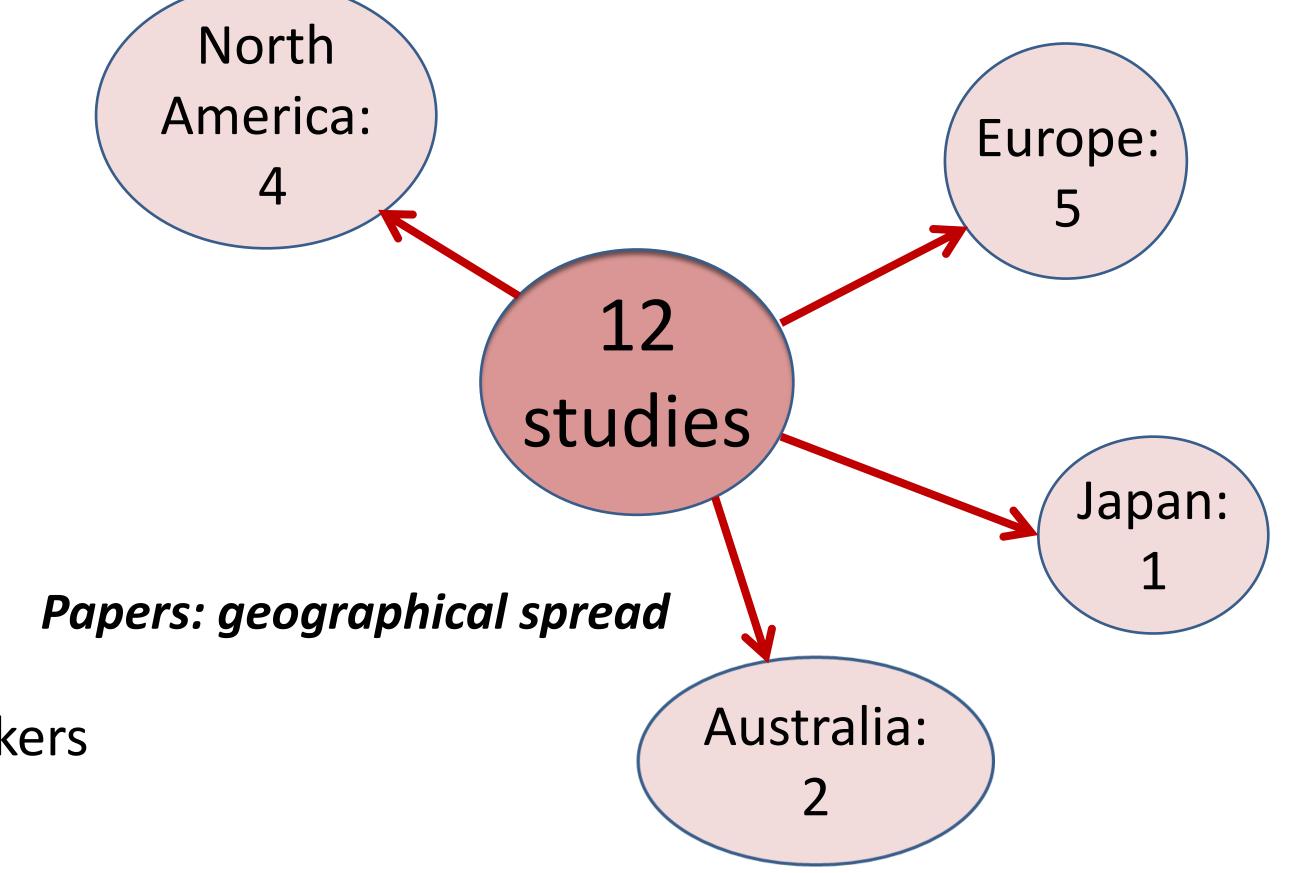
## Background

An ageing population heralds a greater demand for palliative and end of life care. Many people approaching the end of life rely on domiciliary care services provided by a para-professional workforce. Little is known about the impact of this work on the workers themselves or how they are trained, supervised and supported.

## **Review question**

'What are the work and training experiences of social care workers providing home care to those approaching the end of life?'





### Method and results

A systematic search of six databases was conducted.

#### assistants SDCWs health aides HPCAs social carer unlicensed generic home specialist care providers community

A multiplicity of worker job titles

All study designs were included. Titles and abstracts of retrieved papers were screened by two researchers working independently. 747 records were screened, 12 papers constituting an international spread were included in the review demonstrating a paucity of research on this topic.

## **Review findings**

A multiplicity of job titles makes identification and comparison of worker experiences problematic

- The experiences of workers providing palliative care is of international concern
- There is wide variation in the frequency and length of worker contact time with clients
- There is a lack of preparedness and organisational support and supervision for direct care workers in this field
  - Training gaps and needs are often unmet or not sustained
- Establishing rapport and building relationships with those cared for can lead to blurred boundaries and difficult grief issues for direct care workers

## Key questions for further research...

What are the parameters of direct care worker roles in palliative and end of life care contexts? What systems do employing agencies need to adopt to better train and support these workers?

What are the financial and other constraints in this sector that impact the quality of worker experience?



For further information: sean.hughes@lancaster.ac.uk