Supporting the homecare workforce in providing care for people with dementia up to the end of life

Findings from a systematic review

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Context to the study

- Rising number of people living with, and dying from, dementia\(^1\)
- Resourcing needed for the option of dying at home for people with dementia\(^2\)

1. Alzheimer’s Research UK, 2014
2. Department of Health, 2013
Home care workers:

- are the largest dementia care workforce\(^1\)
- provide practical care and support to many older people with dementia at home up to time of death

1. Hussein, 2010
• Little is known about workers’ perspectives and experiences supporting people with dementia up to the end of life
Study Overview

18 month study, funded by Dunhill Medical Trust

**Phase 1:** Systematic literature review

**Phase 2:** Qualitative interview study to investigate home care worker’s views and experiences of working with people with dementia at end of life

- 40 home care workers & managers
- From 4-6 care home agencies
- South-East England & London
Methods of Systematic Review

- 8 electronic databases:
  - Social sciences [ASSIA and Sociological Abstracts]
  - Nursing [CINAHL]
  - Biomedical sciences [EMBASE]
  - Multidisciplinary research forums [SCOPUS and Web of Science]
  - Healthcare systematic reviews [Cochrane Database of Systematic Reviews and Cochrane Central Register of Controlled Trials]
<table>
<thead>
<tr>
<th>Topic of interest</th>
<th>Search terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homecare worker</td>
<td>Home care aide, home health aide, personal care aide/assistant/attendant,</td>
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<tr>
<td></td>
<td>direct care worker, domiciliary worker and support worker.</td>
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<tr>
<td>Dementia</td>
<td>Dementia, Alzheimer’s</td>
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<tr>
<td>End of life</td>
<td>End of life, death, dying, palliative care</td>
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Findings

- Value of job role
- Emotional labour
- Limited preparation
Value of job role

- Role ambiguity and lack of role validation
- Feeling part of a team
- Remuneration
Emotional labour

- Dementia-related work stress
- Emotional strain related to end of life care
- Limited emotional support
Limited preparation

- Limited client information to prepare them for the role

- Need for dementia-specific end of life training
Discussion

• Why no empirical research on home care workers, dementia, and end of life care?
• Knowledge gap about experiences, beliefs, and views of home care workers
• Implications of emotional labour – with clients? with family? with professionals?
• At a time when specialism is in vogue (e.g. dementia home care workers), do we need another specialism (e.g. end of life and dementia)?
Conclusion

• A paucity of research exists on experiences of home care workers providing end of life care for people with dementia

• Rising demographics and social trends indicate clear need for research, preparation, and support for these care workers

• Without an evidence base, home care managers lack guidance to deliver effective end-of-life care
References

https://www.alzheimers.org.uk/statistics

Department of Health (2013) Improving Care for People at the End of their Life. London: DH.
https://www.gov.uk/government/policies/end-of-life-care

Thank you!

Any questions?
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