

“WORKING TO THE END”

Experiences of the home care workforce
providing end of life care



Home Care Forum, September 2017

Kingston University
London

**Kritika Samsi, Jill Manthorpe,
Tushna Vandrevala**

**SOCIAL
CARE
WORKFORCE
RESEARCH
UNIT**

KING'S
College
LONDON

Research team & acknowledgements

- Research team:
- Investigators – Jill Manthorpe (KCL), Tushna Vandrevalla (Kingston), Kritika Samsi (KCL)
- Researchers – Ruth Abrams & I-ling Yeh (Kingston)
- Funder & Disclaimer: This study has been funded by Dunhill Medical Trust (Grant reference number: R433/0715). The views in this presentation are those of the authors and not necessarily those of the funder.
- Acknowledgements: Thank you to all participants who gave us their time and shared their views with us. Thanks also to Valerie D'Astous for recruiting and conducting the research interviews.



Background to study

- More older people being diagnosed, living and dying with dementia [1]
- People with dementia (and others) wishing to live in their own homes for as long as possible
- Government policy in UK encourages people to 'die in place' [2]
- Yet hard to tell when end of life is approaching



- Homecare workers are largest dementia care workforce in UK and provide social care to people with dementia – including at end of life [3]
- Tasks = ambiguous (intersection of personal and professional)[4]
- Little known of subjective experiences of home care workers [5]



Aims of the study

To explore **experiences** of home care workers providing end of life care to people with dementia living in their own homes

To elicit the role of home care workers, the everyday challenges they encounter and how these are **managed**

To understand the **impact** of the work, and the ways in which home care workers cope, “switch off” from work

Method

- Face-to-face, semi-structured interviews were conducted
- Asked about their everyday roles, especially at eol, challenges encountered and coping strategies
- Participants received a £20 voucher as a thank you for taking part
- Framework Analysis used to identify themes and interpret patterns in the data [6]
- Ethical issues thoroughly considered

Sample

- 62 home care agencies contacted around central London and S.E. England
- 10 agencies agreed to participate (3 in S.E. England & 7 in central London)
- 43 interviews – 30 home care workers + 13 managers

Findings

Themes

1. Contribution of homecare workers at the end of life

2. Blurred role boundaries and other challenges

3. Impact of work

4. Support & gaps in support

Findings

Themes

1. Contribution of homecare workers at the end of life

2. Blurred role boundaries and other challenges

3. Impact of work

4. Support & gaps in support

Contribution of home care workers at end of life

- Range of tasks undertaken by home care workers
- Work often dictated by formal procedures, set by homecare and regulatory agencies
- Need to blend and adapt into various home environments, family dynamics, personal care needs and values

-
- Perception of job role and personal value

“One day, I was down washing her knees and things like that and her legs, and all of a sudden, I could feel her touch me and she went like this all down my face [strokes face], and gave me a beautiful smile. It was wonderful. It’s as if to say, I know what you are doing and thank you. It was lovely”

(Female homecare worker, 9 months in current role, aged over 60)

Findings

Themes

1. Contribution of homecare workers at the end of life

2. Blurred role boundaries and other challenges

3. Impact of work

4. Support & gaps in support

Blurred boundaries and other challenges

- Adaptability sometimes led to blurring of role boundaries

“She said to me, "Can you change my dressing?" And I said, "I am not allowed to change your dressing." She went, "Well, the district nurse said you can do it." I said, "No, I can't do it, obviously I am not trained to do it.”

(Female homecare worker, 7 years in current role, aged between 41-50)

-
- Formal procedures and policies may help but in practice many unresolved responsibilities/requests

“The daughter asked if we could clean her [mother’s body] up and we had to apologise more than twice and say we’re really sorry, we’re not allowed to, it’s against company procedures to do that. And in my head I said, if I could do it, I would do it, I’d gladly do it, I mean just to give her a little bit of more dignity”

(Female homecare worker, 5 years in current role, aged between 25-40)

Findings

Themes

1. Contribution of homecare workers at the end of life

2. Blurred role boundaries and other challenges

3. Impact of work

4. Support & gaps in support

Impact of work

- Questioning own mortality
- Some planned for their own care – Power of Attorney, discussed care choices with own family
- Double edged sword of becoming attached to clients

“You know, you watch them taking daily steps going downhill, not uphill, but going downhill. And it breaks you, you probably feel it more than the family. And then while you are there you are giving them comfort and stuff like that and, you know, it's end of life really so you know it's not going to be the best thing, no matter what you say it's never going to be, you know, comforting but you're still trying to put your best out there. But it's very, very hard”

(Female home care worker, 10 years in current role, aged between 41-50)

- Emotional labour

“It was like the initial shock of once I knew, or got the confirmation when the husband broke down and started crying and calling her name, it's just like, I got like a ball, it's like a knot in my stomach and it's like a burning sensation and then instantly my hands started shaking and I felt like I was going to faint, so I said okay, I just need a little bit of air, let me just go downstairs and try and calm myself down. But that was the first time I walked in on a client and found them passed away”

(Female home care worker, 5 years in current role, aged between 25-40)

Findings

Themes

1. Contribution of homecare workers at the end of life

2. Blurred role boundaries and other challenges

3. Impact of work

4. Support & gaps in support

What helps and what could be better?

- Experience & being prepared with prior information helps
- Personal coping strategies
- Peer support and support from management
- Opportunity to attend funeral helped some with closure

“You know, you become very emotional. You feel that you've not managed to say goodbye to that person properly. By actually going to the funeral, you can just say goodbye to them and say a prayer and say goodbye to them and that's how I feel”

(Female home care worker, 3 months in current role, aged between 25-40)

Implications & Conclusion

- Learn from homecare workers about how best to manage professional role boundaries and how these are negotiated well in everyday practice
- End of life care is not clinical activity alone; home care worker role adaptability enables them to enhance personal relationships and provide person-centred care; is this recognised?
- Acknowledge emotional labour of home care worker role and offer more regular supervision and support
- Encourage avenues for peer support and group mentoring

References

1. Alzheimer's Research UK, (2014), Dementia Report: <https://www.alzheimers.org.uk/statistics>
2. Department of Health (2013) Improving Care for People at the End of their Life. London: DH.
3. Hussein, S. (2011), Estimating probabilities and numbers of direct care workers paid under the National Minimum Wage in the UK: A Bayesian approach. *Social Care Workforce Periodical*, 16. London: King's College London
4. Herber, O.R. and Johnston, B.M. (2013), The role of healthcare support workers in providing palliative and end-of-life care in the community: a systematic literature review, *Health and Social Care in the community*, Vol. 21(3), pp. 225-235.
5. D'Astous, V., Abrams, R., Vandrevalla, T., Sami, K. and Manthorpe, J. (2017), Gaps in understanding the experiences of homecare workers providing care for people with dementia up to the end of life: A systematic review, *Dementia*, Vol 0(0), pp. 1-20.
6. Ritchie, J. and Lewis, J. (2003), *Qualitative research practice: a guide for social science students and researchers*. London: Sage.

THANK YOU

kritika.1.samsi@kcl.ac.uk

jill.manthorpe@kcl.ac.uk

t.vandrevalla@kingston.ac.uk

SOCIAL
CARE
WORKFORCE
RESEARCH
UNIT

KING'S
College
LONDON