Complex roles of home care workers supporting people with dementia approaching end of life

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Research team & acknowledgements

• Research team:
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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], particularly relating to working with pwd and upto the end of life
Study design

18 month qualitative interview study aimed to:

- Explore experiences of home care workers providing end of life care to people with dementia living in their own homes
- Elicit the role of home care workers, the everyday challenges they encounter and how these are managed
- Understand impact of the work, and the ways in which home care workers cope, “switch off” from work
• 10 home care agencies (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

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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
## Findings

### Themes

1. Contribution of homecare workers at the end of life

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Blurred boundaries and other challenges

• Adaptability of job role sometimes led to blurring of role boundaries

• And confusion amongst clients and other care professionals

• 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

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Impact of work

• Led to questioning own mortality

• Working alone with clients with complex needs

• Double edged sword of becoming attached to clients and their families

• Impact of emotional labour of caring
“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

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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
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 more than just clinical activity; 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, especially working alone, with complex clients, and offer more regular supervision and support.

Encourage avenues for peer support and group mentoring.
References

2. Department of Health (2013) Improving Care for People at the End of their Life. London: DH.
THANK YOU

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