Struggling to maintain professional boundaries for care home workers providing end of life care for residents with dementia

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Social Care and Care Homes: The UK context

• In 2011, more than a quarter of a million (291,000) people aged 65 and over were living in care homes in England and Wales, representing 3.2% of the total population at this age (Office of National Statistics, 2014)

• Long-term care facilities Residential and Nursing Care Home

• Privately owned and state contracts
Background

• Current UK government policy encourages people to ‘die in place’ (Department of Health, 2013; Leadership Alliance for the Care of Dying People, 2012).

• Increase in people dying at home and in care homes (National End-of-life Care Intelligence Network, 2013).

• Older people with dementia are more likely to die in care homes than other settings (Moriarty, Rutter, Ross & Holmes, 2012).
Gaps in the evidence

- Research focused on ways in which care home staff make end of life (EOL) care decisions (e.g. Goodman et al., 2010).

- Psychological impacts of caring for dying dementia residents on care home staff unknown.

- Providing EOL care potentially compounds the expectations placed on staff.
Staff working with people with advanced dementia at risk of high levels of stress and burnout

• Staff feel under pressure with the lack of time and increased workload

• Physical nature of care work may lead to injuries and contribute to staff absenteeism

• Residents’ challenging behaviours linked to emotional exhaustion and depersonalisation

• Perception of lack of dementia specific training results in stress

(Carr 2014; Hudson & Moore, 2009; Pitfield et al., 2011; Scott et al., 2011; Stacpoole et al., 2014; Zimmerman et al., 2005)
Providing end of life care potentially compounds the expectations placed on staff in care homes

• Staff uncomfortable broaching the topic of death (Livingston et al., 2011)

• Repeatedly confronting death create stress (Katz et al, 2001; Sidell et al, 2003)

• Providing end of life care entails physical but also emotional labour

• “Emotional Labour”: consciously suppressing inner emotions to enable working effectively - widely reported among professionals working in palliative care (Sorensen & Iedema, 2009; Ryan, Seymour & Ryder, 2013).
Research Methodology

Aim:
Investigate the impacts of working with people with dementia at the end of life on care home staff and how they coped with the stress of such work

Participants and Recruitment
Twenty staff members from 5 care homes in Southern England (Male: 2, Female: 18; British = 16, 3 European, 1 Asian)

Data analysis
Thematic Analysis (Braun & Clarke, 2006)
Findings

Complexities of working with people with dementia

Emotional labour of caring for dying residents

Managing the stress and anxiety of caring at the end of life

*Photo Credit: Telegraph*
Competing Demands

- Multiple job demands, time pressures and growing dependence of residents contributing to stress

- Each resident’s needs pressing and urgent – exacerbated at the end of life.

- The responsibility yet feelings of not having requisite skills

“Sometimes you feel like you don’t really have enough time for them. The half an hour that I help one person in the morning might actually be the only half hour that they actually talk to someone that day one to one, but I am stressed because I have to run off and help someone else.” (Natasha, 8 months’ experience)
Difficulties associated with communicating with residents

• Communication difficulties - people with dementia in the later stages of life are unable to express their wants and needs led to staff distress and compromised quality of care.

• Challenging behaviours associated with some types of severe dementia (such as aggression and other behavioural problems) made them feel afraid and anxious.

• Aggression in dementia is usually a symptom of unmet needs (an attempt to communicate), and not a symptom of the disease itself.

“When some of the clients cannot communicate, we find it difficult, we don’t really know what they want. They cannot communicate to you properly, so you really have to just think for them and try to understand what they want. It can be very frustrating, because you don’t really know what they want and they are trying to tell you what they want and then you try to guess. And they keep saying that it’s not what they want.” (Noella, 10 years’ experience)
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Frequent encounters of death

• Staff felt they took on a significant fictive familial role in many residents’ lives when family were absent - the death of a resident affected them deeply
• Staff ran the risk of identifying too closely with dying residents and this could lead them to confront their own mortality and that of their close family

“At the end it is sad... in the last stage we spend more time with them than their families, you get more attached to them. Most of them treat us like family. I spend more time with the residents than my own wife. It’s like the death of a family member. I don’t have any family here, apart from my wife. I wish I could look after my parents, but I’m here. For me they (residents) are like my parents. Emotionally it’s very difficult”. (John, 5 years’ experience)
Being unable to reduce suffering of residents with dementia

• Felt helpless and powerless about their inability to reduce pain and suffering.
• Frustration on having to rely on external (not on site) clinical help
• Required to act professionally, remain detached and not express this sadness and discomfort at the approaching death

“I feel very stressed when the client is sick and dying and unable to help themselves... especially when it is someone who cannot really explain what is wrong.” (Noella, 10 years’ experience)
Supporting families

• Emotional support to both residents and their families.

• Unrealistic demands on staff or were in denial of their relative’s current health status.

• Helped alleviate stress when they expressed gratitude towards staff for the care they provided.
Findings

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Photo Credit: Telegraph
Wish for dementia specific end of life training

• Insufficient training opportunities

• Underlying assumption that the job would become easier and stress levels would decrease as they became more experienced

• Desire for dementia specific training to include interpersonal skills and communication skills was expressed rather than clinical or practical forms of training

“You’re feeling helpless and responsible really... the responsibility, the thought of what could have happened. Are you right for this job, sort of thing.” (Pat, 18 years’ experience)
Coping with emotional labour

• Need for support in managing the uncertainty and helplessness
• Staff built strong relationships with residents and their families but felt uncertain about their roles in the last few days & weeks before their death
• Others addressed medical aspects of care, but having undertaken intimate tasks made them feel more distressed when residents died
• A ‘space’ and a channel to grieve to manage the anxieties associated with the emotional aspects of their role
Peer Support at work

• Support from colleagues and managers
• Importance of having “emotional outlets” in the workplace and a culture where death and dying were openly discussed.
• If needs unmet, adverse reaction on their physical and psychological health and isolated

“At times it could be slightly difficult, because you kind of want to talk about it, but then you don’t want to upset, burden your colleagues. It’s not fair on them.” (Natasha, 8 months’ experience)
Discussion

• Emotional labour of caring for residents and their families at the end of life source of stress and anxiety, exacerbated by limited training and unmet needs for emotional support

• Staff struggle with finding the balance to remain detached to protect themselves from grief

• Staff may conceal their emotions by keeping themselves too busy to allow time for self-reflection and their attachments to residents are “unacknowledged and possibly unallowable” in a care home (Livingson et al., 2011, p.27).

• Healthcare professionals working within end of life care are also at risk of compassion fatigue (Meadors & Lamson, 2008) and vicarious traumatisation (Sabo, 2008).
Implications for practice and policy

• Emotional aspects of the caring role acknowledged

• Psychosocial interventions, Person-Centred Care and Dementia Care Mapping potential reduce burnout among care home staff (Jeon et al., 2012; Talbot & Brewer, 2015)

• Shift from task oriented training to encouraging an individualised person-centred care or a relationship-centred approach
  – Support to help them address their own grief
  – Supportive colleagues and managers
  – open communication and discussion regarding death, bereavement and grief
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