Using evidence for change

What works to support care at home staff providing palliative and end of life care?

Evidence from published research

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Introduction

A comprehensive search of published research was undertaken to answer two related questions:

1. *What capabilities and support do social care and care at home staff need in providing palliative and end of life care?*

2. *What solutions can help to build these capabilities and provide this support?*

Only five relevant published research studies were identified after comprehensive searching. Although small in number, these yield valuable information to help address the two key questions.

The numbers in the report refer to the evidence summaries detailed at the end of the paper.

Summary of key findings

The recent report by Scottish Care (1) captures the essence of the challenge:

> *Palliative and end of life care involves delivering highly skilled, technical and practical interventions but also providing emotional support, a familiar face, a hand to hold, family liaison and so many more forms of care and support that cannot be captured in any job title. What's more, this is part of a wider remit and not in a specific palliative and end of life care role, therefore protected time and specialist training is often limited or even non-existent.*

Role and capabilities

Care at home staff have a complex, challenging and emotionally demanding role in delivering palliative and end of life care (1). In addition to personal care, their other roles include emotional and social support, care for the dying, respite care for family members and domestic support (1, 2).

The Scottish Care research (1) draws out the following capabilities as key to the care at home worker role in providing palliative and end of life care:

- Emotional intelligence

- Relationship-based care

- Communication skills

- Supporting anticipatory care planning

- Personal resilience

Challenges

Several research sources confirm the challenges they experience in terms of emotional attachment and grief after bereavement; feeling isolated, unprepared and insufficiently trained for end of life care, and lack of clarity about the boundaries of their role compared with other members of the health and care network (1, 2, 3).

Support and solutions

The support and solutions highlighted in the research literature can be broken into three categories:

- Information and knowledge support

- Training

- Improvement opportunities

Information and knowledge support

Information provision and information sharing – ranging from provision of basic information to make the care at home worker aware prior to a visit that a client is dying, to understanding of the visits and interventions provided by other members of the health and care network (1,3).

Provision of guidance and information resources specific to the care at home frontline worker role (1).

Informal peer support groups to share experiences of end of life care and build a sense of cohesiveness among care at home staff (3).

Training

Including:

- Managing the experience of grief and bereavement (1, 2)
- Communication skills – including talking about dying (1)
- Recognising signs and symptoms of dying (1)
- Person-centred and relationship-based care (1,2)
- Anticipatory care planning (1)
- How to prepare for a client dying (1, 2)
- Existential issues - i.e. finding meaning in life and dying (4)

Specific learning methods recommended in the research include:

- Including palliative and end of life care in care at home worker induction programmes (3)

- A defined period of preceptorship / mentorship (3)

- Supervision (3)

- Reflection (4)

- Building experience in palliative and end of life care (though care at home workers were clear that this should not be seen as a substitute for training) (1).

Improvement opportunities

Improving collaborative working with the wider multi-agency health and care network, particularly with district nurses and palliative care nurses (1, 3).

Providing greater ***clarity on the boundaries of the care at home worker rol***e, and when other members of the care network should be involved (1, 3).

Debriefing, counselling and support following experience of a death (1, 3).

Evidence summaries

1. Scottish Care (2017)

[Trees that bend in the wind: exploring the experiences of front line support workers delivering palliative and end of life care](#)

Objectives:

To articulate the experiences of front line support workers engaged in palliative and end of life care of older people in Scotland, and what is means for future commissioning contractual arrangements

Study population:

22 care at home staff from Dumfries, Glasgow, Inverness, Edinburgh.

27 care home staff from the same areas

1 student

Methods:

Focus groups and narrative methodology – gathering the stories of participants.

Findings:

The dying journey is different for each individual, but common elements of a "good" journey include dying where the person wants, how they want and knowing that what they wished for is followed and respected.

Care workers have a complex, challenging and emotionally demanding role in delivering palliative and end of life care. Key capabilities and enablers identified in this study include:

1. Emotional intelligence
2. Relationship-based care

3.   Communication skills

4.   Supporting anticipatory care planning

5.   Partnership working with the wider health and care network – this was a particular gap for care at home workers who often felt isolated and without support.

6.   Information sharing – ranging from provision of basic information to make the care at home worker aware prior to a visit that a client is dying, to understanding of the visits and interventions provided by other members of the health and care network.

7.   Experience helps to build confidence, but training is also essential.

8.   Debriefing, counselling and support for care workers following experience of a death.

9.   Personal resilience.

Recommendations:

1.   Maximise the timely and effective use of palliative and end of life care resources at a local level – including greater collaboration across the multi-agency health and care network, and providing tailored resources for care at home staff.

2.   Develop equal pathways through palliative and end of life care, so that dying with frailty and dementia have a dedicated pathway in the same way as cancer and other conditions.

3.   Promote the use of anticipatory care plans (acps) for palliative and end of life care

4.   Get better at talking about dying

5.   Make care of the dying a positive career choice

6. Put care homes and care at home services at the heart of palliative and end of life care education

7. Ensure staff – and families – have access to bereavement and counselling services

8. Ensure palliative and end of life care support and training is specifically targeted at the needs of the front line workforce

9. Change commissioning approaches so that provision of solace at end of life is appropriately valued.

10. Rearticulate the role of a front line social care worker

11. Provide better support to employers to enable them to support solace

12. Protect the physical and mental health and wellbeing of the workforce.

2. Boerner, K ; Burack, OR; Jopp, DS.; Mock, SE (2015)

[Grief After Patient Death: Direct Care Staff in Nursing Homes and Homecare](#)

Journal article

Objectives:

1) determine how grief symptoms typically reported by bereaved family caregivers are experienced among direct care staff, 2) explore how prepared staff members were for the death of their patients, and 3) identify characteristics associated with their grief.

Study population:

US study

80 homecare workers

140 certified nursing assistants

Methods:

Cross-sectional study using standardized assessments and structured questions to address staff (e.g., preparedness for death), institutional (e.g., support availability), and patient/relational factors (e.g., relationship quality). Data analyses included bivariate group comparisons and hierarchical regression.

Findings:

Grief reactions of staff reflected many of the core grief symptoms reported by bereaved family caregivers in a large-scale caregiving study. Feelings of being "not at all prepared" for the death and struggling with "acceptance of death" were prevalent among staff. Grief was more intense when staff-patient relationships were closer, care was provided for longer, and staff felt emotionally unprepared for the death.

Recommendations:

Increasing preparedness for this experience via better training and support is likely to improve the occupational experience of direct care workers, and ultimately allow them to provide better palliative care in nursing homes and homecare.

3. Herber, OR: Johnson, BM (2013)

[The role of healthcare support workers in providing palliative and end-of-life care in the community: a systematic literature review](#)

Journal article

Objectives:

To address two questions:

1. What particular tasks/roles do healthcare support workers (HCSWs) perform when caring for people at the end of life and their families to comply with their desire to remain at home?;
2. What are the challenges and supporting factors that influence HCSWs' ability to provide palliative and end-of-life care in the community?

Methods:

Systematic review combining quantitative and qualitative research in the 2-year period 990 until April 2011. 9 papers met inclusion and quality criteria; 5 from US; 4 from UK. 2 studies (both UK) involved care at home workers – a total of 106 in interviews; additional 6 in a focus group.

Note: although described as "healthcare" support workers, the role as described seems consistent with that of social care homecare staff.

Findings:

- HCSWs provide:
    - Personal care
    - Emotional and social support
    - Care for the dying
    - Respite care for family members
    - Domestic support
- Three challenges were identified in the HCSWs role:
    - Emotional attachment
    - Role ambiguity
    - Inadequate training.
- Support factors which helped HCSWs to overcome these challenges included:
    - Informal peer grief-support groups
    - Sense of cohesiveness among HCSWs
    - Task orientation – i.e focusing on getting the job in hand done rather than focusing on people.

Recommendations:

To help reduce the challenges identified in HCSWs' roles, the following approaches are recommended:

- Induction and training programmes
- A defined period of preceptorship
- Appropriate support
- Supervision
- Clearly defined role boundaries.

4. Henoch,I; Danielson,El; Strang,S; Browall,M; Melin-Johansson,C (2013)

[Training Intervention for Health Care Staff in the Provision of Existential Support to Patients With Cancer: A Randomized, Controlled Study](#)

Journal article

Objectives:

To determine the effects of a training intervention, where the focus is on existential issues and nurses' perceived confidence in communication and their attitude toward caring for dying patients.

Study population:

102 nurses in oncology and hospice wards and in palliative home care teams in Sweden.

Method:

Randomised controlled trial

Findings:

Confidence in communication improved significantly in the training group from baseline (before the training) immediately after the training and five months later.

Recommendations:

Short-term training with reflection improves the confidence of health care staff when communicating, which is important for health care managers with limited resources.

5. Watanabe, M; Yamamoto-Mitani, N; Nishigaki, M; Okamoto, Y; Igarashi, A; Suzuki, M (2013)

[Care managers' confidence in managing home-based end-of-life care: a cross sectional study](#)

Journal article

Objective:

To examine the confidence of care managers at managing home-based end of life situations and what factors influence their confidence levels.

Study population:

450 care managers from 1,200 homecare agencies in Japan.

Methodology:

Cross-sectional study with systematic sampling.

Questionnaire survey.

Multiple logistic regression analysis to identify factors influencing confidence levels.

Findings:

70% of CMs expressed some level of confidence in managing home-based end of life situations. Others reported anxiety, difficulties and low confidence in managing such care Higher levels of confidence were significantly associated with:

- having a nursing license

- experience of working as a homecare nurse or a home attendant

- multiple experiences with end of life situations, compared with those who had none, or only one experience.

Recommendations:

Given that the number of nurses working as care managers is decreasing, further research is needed to explore what support care managers need to increase their confidence, especially when they do not have nursing licenses and/or experience with end of life situations.

References

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