Using evidence for change

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

Evidence from improvement knowledge

Sheila Inglis, SMCI Associates

Edited by Stuart Muirhead, Iriss

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Contents

Aim and scope of this work

This strand of work aimed to identify learning from improvement to help to answer the 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?*

This improvement knowledge will complement and augment the formally published research retrieved through a separate work strand. It aims to capture real-life examples of improvement, recommendations for service improvement, evaluation reports, practice development and piloting / scoping initiatives. Work of this nature is often not published in the peer-reviewed journal literature. It is more likely to be found in case studies, abstracts from conferences and meetings, pilot studies and project reports published informally or locally within organisations.

Moreover, this type of knowledge is often tacit – i.e. knowledge that people hold in their heads, based on their experience, rather than writing it down. This means that sometimes it can only be articulated in discussion – e.g. in interviews, storytelling or focus groups. For this reason, key contacts have been identified, as well as documented reports, so that stakeholders can learn more by getting in touch with key individuals that hold this valuable tacit knowledge.

The numbers in the text refer to the three improvement references described at the end of the report.

Summary of key findings

Capabilities needed by care at home workers

Participants in the Codling et al report (3) gave a rich picture of the range of knowledge, skills and personal qualities needed for this role, including:

- Diplomacy
- Communication – including listening skills
- Empathy
- Relationship building
- Medicines management
- Ability to source information on the Internet and to signpost to sources of information and support.
- Knowledge of financial information sources
- Risk analysis
- Problem solving
- Recording skills
- Being a team player.
- Flexibility

They highlighted the need for a range of personal qualities including:

- Compassion
- Understanding
- Respect
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Challenges

Key areas in which care at home workers in this study (3) felt inadequately prepared for the role were:

- Communicating with a person about end of life, when to do this and the role of the family.

- Recognising pain, managing pain
- Which members of the wider health and care team to contact for support.

Support and solutions

The support and solutions highlighted in these improvement and evaluation reports fall into three categories:

- Information and knowledge support
- Training
- Improvement opportunities

Information and knowledge support

This section and the adjoining numbers relate to the papers summarised in the *References and Key Points Section*.

A shared communication sheet (1)

- Draft person-centred end of life care questions for social care worker interviews with service users (1)
- Improved IT systems enabling better data sharing between health and social care professionals (2)
- More joined-up discussions between all health and care professionals involved in the delivery of care to people at end of life, to support care at home workers (3).
- More opportunities to talk about death and dying (3).
- Information and guidance about accessing wider care services for people with learning disabilities at end-of-life care (3).

Training

- Leadership development (2)
- Building resilience (2)

- Mandatory core training in palliative care and bereavement issues for all care at home, nursing and care home staff (2).
- Communication training to support staff in sensitive conversations about death and dying (2)
- Training in anticipatory care planning to ensure a person's preferences, choices and wishes are accurately recorded (2,3).
- Training in person centred care (3)
- Supervision (3)
- Learning about recognising and treating pain, including assessment tools (3)
- Training about services to access in the wider health and care network (3)

Specific learning and development approaches highlighted as likely to be appropriate included:

- Support and training from professionals who are at the forefront of care delivery – e.g. district nurses, palliative care nurses (3).
- Supervision (3)

Training content was described in detail for a study day in one report (3). This training was based on the six steps of care model (NHS National End-of-Life Care Programme, 2011). It included:

- End-of-life care and identification of this stage
- Opportunities for paid carers to hear individuals with learning disabilities talk about their end-of-life wishes and to make advance care plans, while appreciating the challenges they may encounter
- Local services available to support people with learning disabilities in end-of-life care and how they can be accessed
- The impact of paid carers' own beliefs, values and needs relating to death and dying
- The physical, psychological, spiritual and social issues that may arise when caring for a dying person.

Improvement opportunities

Reference 1 provides a comprehensive proposal for improving the model of palliative care, including the role of care at home staff. This is based on a rigorous analysis of evidence, and consultation with health and social care staff and carers in the City of Edinburgh Homecare and Reablement Service. The model is illustrated below:
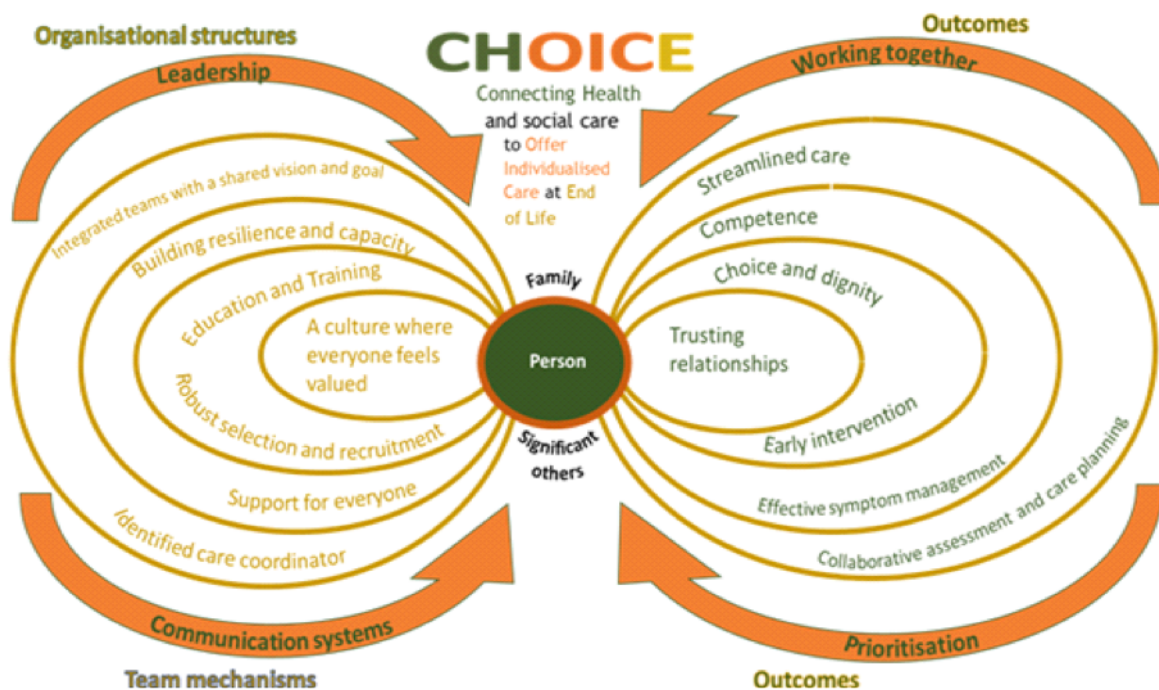
The model has still to be tested in practice, however many of the key elements it highlights merit development in their own right – e.g.

- Integrated team working across agencies – including collaborative assessment and care planning (also highlighted as an improvement need in reference 2).
- Leadership development
- Building resilience
- Education and training

- Improved communication systems (also highlighted as an improvement need in reference 2)
- An identified care coordinator
- Building trusting relationships

The Marie Curie report on social care at the end of life (2) identified additional strategic areas for improvement:

- Improved IT systems enabling better data sharing between health and social care professionals.
- Eliminating unnecessary delays between assessment and provision of support.
- Responsive social care packages that can adapt quickly to changes in need.
- Designing age appropriate support – e.g. respite care and care homes are often not designed for the under-65s.

References and key points

1.Dickson, C; Kelly, H; Logan, J, 2015, Queen Margaret University

[CHOICE: Connecting Health and social care to offer individualised care at end of life](#)

Report of a pilot project.

Objective:

To develop and pilot test an initial framework of integrated working to facilitate person-centred care for patients and families at the end of their life who are being cared for in their home.

Study population:

City of Edinburgh Home Care and Re-ablement Service - community nurses, social care workers and family carers

Methods:

Mixed-method approach including participatory research, realist synthesis, person-centred practice, practice development and active learning.

Results:

An evidence-based, person-centred model of integrated multi-agency working (see illustration in summary above) was developed through a participative approach involving staff at all levels, and informal carers. Practical outputs included:

- A shared communication sheet
- Draft person-centred end of life care questions for social care worker interviews
- Education sessions

- Informal drop-in sessions to address social care workers' development needs.

Unfortunately the model was not able to be tested during end of life care with patients and families.

Recommendations:

This model, developed as it is through a combination of analysis of the research evidence and stakeholder engagement, has the potential to develop practice in an integrated, person-centred way, although further testing is required in practice. Key approaches recommended in this model include:

- Leadership development
- Integrated team working across agencies – including collaborative assessment and care planning.
- Building resilience
- Education and training
- Improved communication systems
- An identified care coordinator
- Building trusting relationships

2. Marie Curie, 2016

[Dying to care: a report into social care at the end of life](#)

Report

Objectives:

- To describe the role social care services play in supporting people with palliative care needs or at the end of life in Scotland.
- To highlight opportunities for improvement so that greater collaboration with social care and more creative use of social care services can help to achieve the aims of the national Strategic Framework for Action on Palliative and End of Life Care - i.e. helping

people to remain at home, get out of hospital, stay connected to their communities and live as well as possible before they die.

Methods:

Analytical and opinion piece.

Recommendations:

Improvement opportunities

Ways identified in which services can improve to ensure that people get the care they need in palliative and end of life situations include:

- Communication – with staff skilled in facilitating conversations about dying
- Greater support for anticipatory care planning
- Improved IT systems enabling better data sharing between health and social care professionals.
- Eliminating unnecessary delays between assessment and provision of support.
- Responsive social care packages that can adapt quickly to changes in need.
- Designing age appropriate support – e.g. respite care and care homes are often not designed for the under-65s.

Education and training

Specific recommendations for education and training for the social care workforce include:

- Mandatory core training in palliative care and bereavement issues for all care at home, nursing and care home staff.
- Communication training to support staff in sensitive conversations about death and dying
- Training in anticipatory care planning to ensure a person's preferences, choices and wishes are accurately recorded.

3. Codling, Mary; Knowles, Jane; Vevers, Ann (2014)

[End-of-life training for paid carers working with people with learning disabilities](#)

Case study/evaluation report (Practice-focused journal article.)

Study population:

43 paid carers in Berkshire Foundation NHS Trust, delivering care to people with learning disabilities in their homes.

Methods:

- Descriptive study and questionnaire-based evaluation.

- Study day was delivered on two sites.

- Training was delivered by a district nurse and a palliative care nurse, based on a structured framework known as the six steps of care (NHS National End-of-Life Care Programme, 2011). The study day provided information on:

  - End-of-life care and identification of this stage

  - Opportunities for paid carers to hear individuals with learning disabilities talk about their end-of-life wishes and to make advance care plans, while appreciating the challenges they may encounter

  - Local services available to support people with learning disabilities in end-of-life care and how they can be accessed

  - The impact of paid carers' own beliefs, values and needs relating to death and dying

  - The physical, psychological, spiritual and social issues that may arise when caring for a dying person.

Findings:

- Capabilities which participants identified as necessary for this role included: Compassion, Diplomacy, Co-coordinating, Respect, Verbal skills, Financial, Empathy, Humour, Medication management, Courage, Problem solving, Research (internet) Caring, Team player, Experience of caring, Listening, Signposting, Recording, Patience, Relationships, Risk analysis, Understanding, Communication, and Flexibility.

- Challenges: Key areas in which paid carers felt inadequately prepared for the role were:

  - Communicating with a person with learning disabilities about end of life, when to do this and the role of the family.

  - Recognising pain, managing pain

  - Who to contact for support.

- Solutions:

  - Approaches participants identified to help them address these challenges included:

  - Training in person centred care and preparing end-of-life plans

  - Opportunities to talk about death and dying

  - Supervision

  - Learning about recognising and treating pain, including assessment tools

  - Training and guidance about services to access in the wider health and care network.

Recommendations:

- Paid carers need support and training from professionals who are at the forefront of care delivery.

- There is a need for more joined-up discussions between all health-care professionals involved in the delivery of care to people with learning disabilities at end of life, to support paid carers and transform death from hospital settings to people's own homes.

- Paid carers need support in the form of information and guidance about accessing wider care services for people with learning disabilities at end-of-life care.