



Real stories: Real insight

Competences

Section 4 of full report

Developing key worker competences for domiciliary care workers to support an integrated pathway for end of life care.

May 2011

Extract from the full report which was published in May 2011.

This document contains sections 1, 4 and 5. It was produced in March 2013, for use with the film of domiciliary care workers in a training pack produced by Skills for Care. This document includes the Executive summary to provide context. It provides those using the short film with necessary detail on:

- key worker role and
- end of life care competences.

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¹ Common Core Competences and principles for health and social care workers working with adults at the end of life document. To support the National End of Life Care Strategy, 2010.

Foreword



In reflecting upon the delivery and outcomes of this project I am reminded that there truly isn't "anything new under the sun" we still seem to live in a world where everybody reckons somebody will sort it out only to find that in the end nobody has...

Throughout my 30 year career, the issue of person centredness has been a constant theme whether we were calling it person centred care or holistic care, multidisciplinary team approaches or integrated care. Similarly professional angst about the quality of care we provide to people facing their end of life is not a new experience. Yet here we are in 2011 still seemingly struggling with the same issues and concerns. Why is that?

I believe that this project helps answer that in part. As you read this report you may find yourself thinking that the findings and conclusions about the role of domiciliary care workers are obvious and indeed nothing new. However there is a more personal challenge within the subtext, namely: how are we as individuals going to act upon the findings to influence what is in our gift to do so? What has stopped us before? Are we prepared to be that somebody who influences everybody else by our action?

Julie Thorpe

**Commissioner of NHS services in Wakefield,
West Yorkshire and Macmillan Nurse**

May 2011

1. Executive summary

A valuable workforce

As people approach end of life, their dependency and needs may increase and the number of services they must navigate grows - the person who is often a 'constant' is their domiciliary care worker (DCW), already providing care in the home. Are they recognised as actually having such a pivotal role? How do we tap into and develop the skill of this workforce? What is required in terms of their competency, attitudes and values to make that possible?

This project focused on the daily experiences of a number of people in two areas of Yorkshire and the Humber region - Hull and Wakefield. It collected their stories and listened to their individual voices to understand how care feels in practice.

They included service users, informal carers, domiciliary care workers and social care managers.

The reason for this project

The number of people requiring supportive end of life care is increasing and it is now a priority for commissioners of health and social care services to understand how best to support carers and people at this most difficult of times. Financial and resource pressures have created an opportunity to commission differently and to use innovative ways of working across agency boundaries in public, private and voluntary sectors.

The research in this project draws upon actual experiences of end of life care. It uses person centred tools and experience based design as methods to articulate and understand. These are the "Real stories" of this report title.

This project begins to address the question of recognising the pivotal role of domiciliary care workers and their potential to fulfil a key worker role. The competences required and benefits of integrated working are also examined. Our findings provide the "Real insight" of this report title.

People's stories have provided the insight

Our project title is "developing key worker competences for domiciliary care workers to support an integrated pathway for end of life care" with specific focus on the trigger points for early identification that a person may be approaching end of life.

We have gained our understanding and insight by using the 'voices' and drawing on the experience of the following groups:

- case studies from Hull, where person centred thinking tools were used to understand the experiences
- focus groups in Wakefield – using experience based design
- domiciliary care workers and manager's experiences
- GP and practice managers perspectives.

The insight we sought required a level of trust and a sensitive method for recruitment. We therefore built upon existing relationships of trust. Hull City Council social services already had a person centred care programme in place. Wakefield District already had developed Community Development Teams. This enabled the team to access effective methods for the selection of individual stories, to remain sensitive to every individual involved and deliver within the timescales.

Key messages for improving end of life services are:

- Person centred thinking used as early as possible irrespective of end of life approaching gives people confidence that they are being listened to and supports their needs.
- Domiciliary care workers displayed many of the competences required to support people and their families at end of life, this workforce should be developed with the support of competency-based learning needs analysis and training to be more involved in the planning of people at end of life.
- Understanding expressed needs through the 'voice' of domiciliary care workers using person centred tools could benefit health professionals when planning with the person their end of life care.
- What makes 'excellence' in care is the underpinning attitudes and values (capability) of care workers as well as skill and competency.
- Assistant level care and support is provided by care workers at a level a person would receive within a hospice or specialist unit and is valued highly by the person and their informal carers.

When considering the themes arising from this project, the similarities displayed between the level of end of life care competences of experienced domiciliary care workers and health care assistants working in end of life care settings was in evidence. It raises the question again about how to develop more integrated approaches at this level for end of life care delivery such as a generic role that supports health and social care.

A call to action

This report is an invitation to the social and health care communities, commissioners, people and their informal carers to draw on the insight from these real stories and help change practice. The project team have plans to make the work sustainable within our local areas and it would be a real return on the investment if others use and build on our work.

Key worker definition

Our proposition is that domiciliary care workers are critical to the effective implementation of the end of life strategy. They already provide support in a large number of households². We have used established definitions of key worker from health and social care to test that proposition.

Key worker definitions in health and social care

Social care:

Defined in Care Co-ordination Network UK - Key worker standards, 2004 as:

‘A key worker is both a source of support for disabled children and young people and their families and a link by which other services are accessed and used effectively. Key workers have responsibility for working together with the family and with professionals from services and for ensuring delivery of an inter-agency care plan for the child and family’.

Health defined in NICE guidance (2004) as:

‘A person who, with the patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice’.

Elements of a key worker

We have aligned both definitions to generate five elements of a key worker role. These are used as the basis of analysis.

Co-ordinating a person’s care - co-ordinating patient’s care (health)/responsible for working together with the family and professionals (social care)

Promoting continuity - promoting continuity (health)/source of support for person and their families (social care)

Empowering the person - with the person’s consent and agreement (health)/source of support and link by which other services are used effectively (social care)

Signposting - ensuring patient knows who to ask (health)/link by which other services are accessed (social care)

Effective team member - effective team member (health)/ensuring delivery of an inter-agency care plan for person and family (social care).

² There are around 350,000 domiciliary and care home workers in Yorkshire and the Humber as at April 2011, National Minimum Data Set for Social Care (NMDS-SC) at www.skillsforcare.org.uk/research.

Key worker definition drawing upon both health and social care

The key worker is not a specified role. Rather it is defined here in terms of competences drawn from the skills for health³ that are applicable to a generic worker role which could operate within various management systems in any sector, public, private or voluntary and community.

For the purposes of our analysis, our definition of key worker is a person or persons who together have the set of competences that need to be in place around the person to support excellence in end of life care.

Table 1: Key worker role defined in terms of the elements of health and social care roles mapped to the Common Core Competences. Letters 'a' to 'g' in the table below refer to the relevant sections of the Common Core Competences shown on pages 9 to 11 of this report.

Common Core Competences		1. Communication skills	2. Assessment and care planning	3. Symptom management	4. Advance care planning	5. Overarching values and knowledge
Definition of key workers (health and social care)	Co-ordinating person's care	a, d	b, e	b	a	e
	Promoting continuity	c, d	e	b, c, d	a	c
	Empowering the person	b, e	c, e,	a, e, g	d	e
	Signposting	e, f a, g	e, f, g --	f		
	Effective team member	a, c a, b, d	a, b, c a	a, e		

³ Common Core Competences and principles for health and social care workers working with adults at the end of life document. To support the National End of Life Care Strategy, 2010.

Table 1, which is on page 7, shows the elements of the key worker role definition drawn from NICE Guidance, 2004 and Care Co-ordination Network UK - Key worker standards, 2004. These have been mapped to the Common Core Competences that would be needed for a domiciliary care worker to operate as a key worker within an integrated pathway for end of life care.

The Department of Health document ‘Common Core Competences and principles for health and social care workers working with adults at the end of life’ states minimum skill and knowledge levels for:

- Group B: staff who frequently deal with end of life care as part of their role
 - need to be enabled to develop or apply existing skills and knowledge to the principles and competences. May require additional specialist training.
- Group C: staff working within other services who are involved with end of life care infrequently
 - a good basic grounding in the principles and competences; alongside knowledge of where to seek expert advice or refer onto.

There are 29 competences in all covering the following skill areas.
(The number refers to how many competences relate to that area)

Communications	5
Assessment and care planning	5
Symptom management and maintaining comfort and well-being	7
Advance care planning	7
Overarching values and knowledge	5

We have reviewed these and 22 of them seem to be essential to the domiciliary care worker to function as a key worker. All 29 are relevant and have been considered within our findings.

Listed on the following pages are the Common Core Competences with their specific dimensions.

Health and social care competences

Common Core Competences and principles for health and social care workers working with adults at the end of life.

There are 29 competences in the tables below of which 22 may be required for a key worker.

1. Communication skills

(5 competences of which 4 - a,b,d,e - may be required for key worker)

- a Communicate with a range of people on a range of matters in a form that is appropriate to them and the situation
- b Develop and maintain communication with people about difficult and complex matters or situations related to end of life care
- c Present information in a range of formats, including written and verbal, as appropriate to the circumstances
- d Listen to individuals, their families and friends about their concerns related to the end of life and provide information and support
- e Work with individuals, their families and friends in a sensitive and flexible manner, demonstrating awareness of the impact of death, dying and bereavement, and recognising that their priorities and ability to communicate may vary over time

2. Assessment and care planning

(5 of which 4 - b,c,d,e - may be required for key worker)

- a Understand the range of assessment tools, and ways of gathering information, and their advantages and disadvantages
- b Assess pain and other symptoms using assessment tools, pain history, appropriate physical examination and relevant investigation
- c Undertake/contribute to multi-disciplinary assessment and information sharing
- d Ensure that all assessments are holistic, including:
 - background information
 - current physical health and prognosis
 - social/occupational well-being
 - psychological and emotional well-being
 - religion and/or spiritual well-being, where appropriate
 - culture and lifestyle aspirations, goals and priorities
 - risk and risk management
 - the needs of families and friends, including carers' assessments'.
- e Regularly review assessments to take account of changing needs, priorities and wishes, and ensure information about changes is properly communicated

3. Symptom management, maintaining comfort and well-being

(7 competences of which 5 - b,c,d,e f - may be required for key worker)

- a Be aware that symptoms have many causes, including the disease itself, its treatment, a concurrent disorder, including depression or anxiety, or other psychological or practical issues
- b Understand the significance of the individual's own perception of their symptoms to any intervention
- c Understand that the underlying causes of a symptom will have an impact upon how care should be delivered
- d Understand the range of therapeutic options available, including drugs, hormone therapy, physical therapies, counselling or other psychological interventions, complementary therapies, surgery, community or practical support
- e In partnership with others, including the individual, their family and friends, develop an end of life care plan which balances disease-specific treatment with other interventions and support that meet the needs of the individual
- f In partnership with others, implement, monitor and review the end of life care plan
- g Awareness of cultural issues that may impact on symptom management

4. Advance care planning

(7 competences of which 4 - a,e,f,g - may be required for key worker)

- a Demonstrate awareness and understanding of advance care planning, and the times at which it would be appropriate
- b Demonstrate awareness and understanding of the legal status and implications of the advance care planning process in accordance with the provisions of the Mental Capacity Act 2005
- c Show understanding of informed consent, and demonstrate the ability to give sufficient information in an appropriate manner
- d Use effective communication skills when having advance care planning discussions as part of ongoing assessment and intervention
- e Work sensitively with families and friends to support them as the individual decides upon their preferences and wishes during the advance care planning process
- f Where appropriate, ensure that the wishes of the individual, as described in an advance care planning statement, are shared (with permission) with other workers
- g When appropriate, know what the advance care planning statement contains, and how this will impact upon an individual's care delivery

5. Overarching values and knowledge

(5 competences and all are required for key worker)

- a In the context of end of life care, understanding and knowledge of:
 - One's own professional/role boundaries.
 - Legal and ethical issues - adherence to legislation and advisory guidance around e.g. Mental Capacity Act and the Mental Health Act.
 - Professional codes of practice or conduct, and their impact on practice.
 - The role/contribution of other workers and organisations to ensure leadership commitment and innovation.
 - The impact of one's own beliefs on practice.
 - Approaches to risk assessment and management.
 - Approaches to and theories of change, loss and bereavement.
 - Social models of care, and person centred approaches.
- b Person centred practice that recognises the circumstances, concerns, goal, beliefs and cultures of the individual, their family and friends, and acknowledges the significance of spiritual, emotional and religious support and the diversities in these regards that there might be between family or social group members
- c Practice that is sensitive to the support needs of family and friends, including children and young people, both as part of end of life care, and following bereavement
- d Awareness of the importance of contributing to evaluation and change of services, participating as appropriate, and of involving the people who use them in that process
- e Taking responsibility for one's own learning and continuing professional development, and contributing to the learning of others

Before moving into the findings section we invite the reader to reflect on the following four stories so that you also begin to focus on the actual people who can benefit.



Real stories written as case studies

This project aimed to include the patients' voices as much as possible and to use this to evidence and explain our conclusions. If we take the concept of the patient's voice to be word for word what was said in conversation, then we do not have this as source. However, if we interpret the "patient's voice" to be a reliable and valid representation of their experiences, concerns, beliefs and emotions, then this can be found in the completed person centred tools that are part of our source material. These tools were used to develop the case studies as a more formal portrayal of the information gathered.

E is an older lady, who has a memory impairment. Her daughter is fully involved in her care, visiting her mother every day. E is well supported by care staff who have adapted what best support looks like for E to make sure that what is important to her continues to be addressed in light of her deteriorating health. For example, E's appearance is extremely important to her, but she is no longer able to visit the hairdresser. Therefore, E's daughter has purchased a wash-cap that staff can use to keep E's hair clean whilst her daughter keeps her company.

In terms of her health care, E feels that visits from the dietician to monitor her BMI are going well. However, all those involved, including E and her daughter, are concerned that although her preferences and wishes are well recorded and acted upon in her day to day care, these have not been recorded with regard to end of life care.

The staff who work with E are particularly keen for this information to be gathered and shared with health staff so that unnecessary hospital admission is avoided as E's health continues to deteriorate.

M is an older person who has dementia. M's husband is very involved in her care and so worked closely with M's care workers to develop the best guesses for how well supported M is. M's husband feels she is well supported by her care workers who work together with M's husband to ensure all care that is provided is as M would wish.

However, neither M's husband nor her care workers feel supported to prevent unnecessary hospital admissions. Both M and her husband find such admissions to be distressing. M becomes particularly anxious during these occasions because she is surrounded by people she does not know. The situation has also been exasperated in the past due to discharges taking place in the middle of the night that then take several hours to occur because of delays at transport section.



J is an older lady living in an extra care unit, who was recently diagnosed with lung cancer. She is a very private lady who likes to take care of her appearance. Domiciliary care staff work closely with J's daughter, who is very involved in her care, to ensure all of her needs and wishes are met. This support helps to ensure J is able to continue to live independently, despite her diagnosis, which is particularly important to J. However, she also fears becoming isolated, so feels reassured by her emergency call button, to which the domiciliary care staff respond immediately.

J can become anxious and the domiciliary care workers take time to address this, by discussing with J her hopes and fears and offering reassurance. The staff will sit with J during this and hold her hand. J loves to chat, so this works well for her.

J is also supported by her GP, district nurses and a Macmillan nurse and, as with the domiciliary care workers, she enjoys a very good relationship with them all.

J feels particularly well supported by her Macmillan nurse, who visits regularly and talks with J, and by her GP who she feels always makes time to sit and talk with her, ask her how she feels and listens closely to what J thinks may help her feel better. J also feels well supported by the domiciliary care workers who make her feel safe in her home.

Despite this good care, J does not feel well supported or cared for when accessing services at the hospital. J has difficulties communicating, which was interpreted by her consultant as being symptomatic of a learning disability. As a consequence of this, best interest meetings were arranged as J was assumed not to have capacity. This is not the case. J has full capacity and is able to make decisions regarding her care, she merely needs to be supported when communicating and given plenty of time. This support is usually provided by the domiciliary care workers and it was these staff that sought to resolve the situation regarding the learning disability misunderstanding.

M is an older lady who has been diagnosed with several conditions: chronic obstructive pulmonary disease (COPD), angina, diabetes, disarticulates, lymphoedema and a skin condition. M also has long standing mental health issues, having struggled with her nerves since her twenties, which often prevents her from functioning with daily living tasks. As part of her treatment for her nerves, M underwent electric therapy. Added to this, M suffered several strokes twenty years ago, which caused her to have left-sided weakness and epilepsy.

M has been unable to walk for several years due to her poor health and has to use a specialised wheelchair. M lives in rented accommodation with her husband, who also has poor health. M is an extremely independent person and takes pride in caring for herself and her husband.

However, as her health deteriorates, M has to receive more care and support herself. Her husband supports M with her health and personal care as best he can, but M also employs two personal assistants using her personal budget to allow her to live an independent life. M also accesses day services on a regular basis through the local authority.

M has been struggling to manage her health issues and concerns. M currently receives care from the practice nurse, district nurse and a long-term conditions nurse. As a result of her deteriorating health, both she and her husband now sleep in the lounge as M is unable to use the stairs. For M, this means sleeping in a recliner, which is very uncomfortable for her legs, whilst her husband sleeps on the settee. Added to this, M feels that the health care she receives is not to the standard or frequency that she would like.

Overall, M feels that the health professionals rarely return her calls, but more specifically there are issues with a number of the services she receives. For example, a particular concern for M is that she feels she does not receive regular support from nurses to dress her legs every day and that when she does, the nurses do not wash her legs and remove the old cream before re-dressing. Similarly, the sores on M's face and scalp are treated with a special shampoo, but as M is unable to use her shower, her hair is not being washed.

In addition, the visit time for the district nurse is unpredictable, so she is unable to plan her day or leave the house when she is expecting a visit. When the district nurse does visit, she talks to M about other patients who are dying, which M finds upsetting and concerning as it breaches confidentiality. It makes M feel guilty if the nurse is then late for her next appointment, so she sometimes tells the nurse to leave her legs.

Meanwhile, M is also concerned that despite being told by the long-term conditions nurse that her blood pressure should be taken fortnightly, the nurse does not have a cuff that is big enough to monitor this. In terms of contact with her doctor, M is unable to access her GP's usual consultation room and so often needs to wait until another room becomes available. This means that sometimes the GP does not actually see M directly, with the consultation merely consisting of messages passed via a nurse. Finally, M also feels that her skin condition, which manifests in sores that are now beginning to appear on her head and neck, is not being adequately addressed, meaning that the sores are worsening and M is left unable to wash her hair.

We are grateful to all the participants of this project and especially the people and their families for their willingness to share their stories. This has meant that we have been able to capture and understand the actual experience of people receiving care and their carers.

End of life is a highly sensitive area of health and social care. We have been able to gather Real insight by building on existing relationships of trust, by being adaptable and sourcing our material using the range of methods explained earlier. This has led to the analysis of findings being a complex job. Nevertheless our findings can help shape the provision of service to support people approaching end of life.

Our project title is: developing key worker competences for domiciliary care workers to support an integrated pathway for end of life care – with specific focus on the trigger points for early identification that a person may be approaching end of life.

Therefore our findings are clustered into:

1 Key worker role

2 Competences required for key worker

3 Integrated care and trigger points to support a DCW in that role

The sources of our findings are explained in full in the methods section of this report and include:

- The case studies from Hull, where person centred thinking tools were used by DCW to understand the experiences and inform care in practice.
- The focus groups of people who had received care; care worker questionnaires and shadowing in Wakefield.
- Interviews with domiciliary care workers and managers.
- Filming to capture the material and provide the basis for independent analysis of competences in evidence.

This findings section outlines the evidence we have gathered to show where the three elements of our project worked well for people at end of life and where action could be taken to look further at practice and make positive changes to support people.

4.1 Key worker role

Our working definition of key worker is taken from the alignment of established definitions in health and in social care. The five elements of the role that come from that are co-ordinating person's care, promoting continuity, empowering people, signposting, and being an effective team member.

We have found that the key worker role relies upon the trajectory towards end of life for people, being in some cases up to a year before death, rather than counted as weeks or days prior to death. If care workers use their skill and knowledge of the person built upon their close personal relationship, then advanced planning and expression of wishes can support the person and their family to prevent unnecessary and often costly events happening such as the need for intensive nursing support and hospital admissions.

Key worker role: summary of findings

- Clear evidence that domiciliary care workers are an integral part of everyday life and are able to provide continuity for the person and their family.
- DCWs empower individuals by understanding their needs and communicating with the person and can include making links to other services.
- In certain examples they are effective team members – both to support each other and link into other professionals.

Key worker role:

What essentials of the key worker role were demonstrated and worked well.

The domiciliary care workers used person centred tools to listen more carefully and deeply to those they support at end of life. The tools used provided a means for focussing their discussions so that the staff could use the emergent information to develop action plans and exact change. In addition, it allowed areas of good practice to be identified, ensuring that this care continues to be provided.

We found strong evidence of co-ordinating care in the following examples of practice, in Hull, with potential for developing this role so that it is recognised by others.

One example of symptom management and maintaining comfort and well-being highlights the key worker role in both co-ordination of care and promoting continuity was displayed by a DCW with a lady with cancer of the throat. She is supported to maintain her independence despite her physical symptoms, and at times feeling isolated. During these times she feels reassured by her emergency call button, to which the DCW responds immediately.

Through evaluations from the DCWs in Wakefield, the time a worker spent with a person was recognised as time when a person could 'open up' and tell the carer things, alert them to any fears and have the difficult type of conversations. This role provided by DCWs clearly is based in the key worker role of promoting continuity and being an effective team worker.

Learning from people at the end of life

One lady's experience of hospital care was as follows:

She has communication difficulties because of throat cancer, she can express herself and communicate given the time to do this, and this is evidenced by the use of the tools with her DCW. The consultant at hospital made assumptions regarding her difficulty of communication and did not use the relationship with the DCW to understand her needs, and went on to assume she did not have mental capacity. This has a great impact on her choices at end of life as she would not have been able to make any and her decisions would have been made at best interest meetings. The lost opportunity of the consultant to understand her wishes through the support of the DCW highlights that here the DCW could act as a key worker to ensure outcomes for her are what she wants.

A person should be able to ask any external visitor (health or social care) for signposting information

'Patients want to be treated with dignity and respect'

Learning from those who support people at the end of life

Key worker definition, DCW – entitled to speak and train? 'When the professionals get involved' care workers defer to the professional occupational therapist, physiotherapist, nurse, I go into the kitchen when they arrive. 'I learnt so much from the care worker who cared for my dad, that is why I became a care worker'.

'It shouldn't matter what badge you come with (social care/NHS), we both have the same aim to treat the patient and care for their needs.'

'It gives me satisfaction to know I am able to make clients as comfortable as possible. They keep their dignity as much as possible and also I feel I am able to give them a good professional standard of care.'

The DCW using person centred tools gives them the confidence to start the conversations regarding end of life care and wishes.



Key worker role - practical thinking: what is still needed as action for the future?

- Person centred thinking has to be part of the care planning for people. When the DCW uses person centred thinking to support plans of care, people report that their needs are being listened to, and the relationship opens the conversations in regards to wishes at end of life.
- The DCW must be part of the multi-disciplinary team supporting the person at end of life, when they are the person receives better holistic care.
- Allow the DCW to embrace the role of key worker; DCWs see part of their job as supporting the person at end of life. In these findings the DCWs interviewed all stated how much they enjoyed and valued the support they gave to the person and support to their family. This was not seen as extra or not their responsibility and sits firmly in the definition of key worker.
- Never under estimate the importance of providing low level care for people and their families. Understanding the 'small' details, makes a person's experience better and creates confidence in supportive care i.e. taste in music, washing hair.

All the above points speak to the health and social care definition of key worker and we saw many examples exhibited in the sources mentioned below.

Sources of this insight for key worker role

- Focus groups of family and carers of people who had recently died.
- Domiciliary care workers questionnaires in Wakefield and evaluation of practice in Hull.

4.2 Competences required for key worker

If DCWs were to be recognised as key workers by health and social care professionals, would they have the competences needed? We have found evidence that domiciliary care workers are well positioned, to take on the five elements of a key worker explained earlier in this report within their current role.

We have built on the work of Skills for Health and Skills for Care⁴ to show the 29 competences that could be required of which 21 were cited by an independent evaluation⁵ to be in evidence using film material of observation and interview. Their findings show that:

“What was very clear was the real evidence that “social care” was being delivered by a caring, compassionate and highly skilled professional social care workforce who universally worked hard to ensure that the care being delivered was person centred”.

Source: Skills for Health Report.

Described below are the findings from the project which highlighted areas of good practice where competency was strong and also areas where development could enhance care delivered. The numbers and small case letters in brackets after each point indicate where we are highlighting evidence from the competency framework in chapter 5.

Competences: summary of findings

- The independent review of the film material found 42 instances that the care workers matched one or more of the competences for end of life care group B and C workers. This material evidenced 21 of the 29 competences.
- There were clear examples of communication skills used to listen and support people and their families and examples of where the DCW discussed the wishes of the person which would support advanced care planning.
- In domiciliary care work not only is it the competences in end of life care that makes a difference to people but also the underlying attitude and ability to empathise. It is this underlying capability plus competence that can make for better outcomes for people at end of life.

⁴ Core competences and principles for End of Life Care: Training for health and social care staff, pbl Skills for Care

⁵ An independent evaluation of 7 hours of film was conducted by Skills for Health to identify individual occurrences and collate evidence of specific competences.

4.2.1 Key worker competency: What competences of domiciliary care workers were demonstrated and worked well.

The type of Common Core Competences either exhibited by staff or required are:

1. Communication skills

2. Assessment and care planning

3. Symptom management, maintaining comfort and well being

4. Advance care planning

5. Overarching values and knowledge

The number referencing used throughout this section draws on this list

Communication skills and the development of good understanding have been shown through the skill of the DCW in listening to the needs of the person and responding appropriately. The confidence instilled in the person and their family was discussed through the Living Well⁶ tools (1e).

All the individuals at end of life who participated in the project in Hull completed the “What is working and not working in my life and what do I want to change?” and “What is important to me now and how do I want to be supported?” tools, enabling an understanding to be gained of their current situations and care and what good support looks like to each individual. This, in the terms of the competency framework, is showing that when person centred thinking is in place, assessment and care planning completed using these tools ensures that all assessments are holistic including social, psychological (5b) as well as plans for managing physical health needs (2d).

Consistently through the tools and questionnaires, the notion that domiciliary care work is much more than the learning of a bunch of competences is inherent, the overarching values and knowledge is crucial to what drives excellence in care. Person centred practice was displayed by DCWs recognising what a person needed when faced with difficult emotional or physical problems. (5b) The time taken with an anxious lady was noted as working well for her, as this allayed her fears by offering her reassurance and the time to chat.

⁶ Living Well tools are produced by <http://www.helensandersonassociates.co.uk/whats-new/new-living-well.aspx> accessed 11April 2014

Despite good care the lady who has communication problems was interpreted by her consultant as being symptomatic of learning disability and as a consequence of this was assumed not to have mental capacity. She needs time and support to communicate and this is given by her DCWs who are trying to resolve the situation regarding the learning disability misunderstanding. Here the overarching values of the DCW are acknowledging the legal and ethical issues surrounding this lady and they are contributing to ensure other organisations understand her needs. (5a)

Learning from people at the end of life

A lady with dementia whose husband is very involved in her care and so works closely with her care workers to develop 'best guesses' for how to support her, feels the care staff support them well.

'The hospice was seen as a place where needs were understood, they had the appropriate training and were open with their communication'

'If only they (health) would treat us like adults and help us understand, then we can make decisions in partnership'

Learning from those who support people at the end of life

'An out-of-hours GP may be called out at a weekend and admit a patient to hospital straight away, unaware of the patient's wishes. There are missed opportunities by health staff to understand the issues around care for people by asking social care staff.'

'We are able to allay their fears and have those kinds of conversations. Key information is discussed with the carer i.e. 'Betty says she doesn't want to go to hospital, I want to die at home'.

In a drive to professionalise generally and promote individual professions specifically lose sight of what makes for excellence in care. We have observations on management culture in a range of settings and its impact. Dispatches, a recent TV programme showed trained nurses who were not kind to their patients. Other industries recruit on 'values' and 'attitude' first and then train for skill and competency.

'Knowing someone is coming to the end of their lives can be upsetting but in the knowledge you have given the up-most care and attention to make the service users last days/weeks/months of their lives as comfortable as possible'.

4.2.2 Practical thinking: What is still needed as action for the future?

The aspects of competences that had a positive impact on care and support for people approaching end of life and their relatives were the following:

- DCWs displayed many of the competences required to support people and their families at end of life, this workforce should be developed with the support of training and competences to be more involved in the planning of care with people at end of life.
- The recognition by all partners that the competences we witnessed can be utilised by any health or social care professional involved in supporting people at end of life.
- To allow a DCW to build on the competences, time has to be factored into the care planning to allow flexibility for the care worker to use their knowledge of what supports the person as their physical and social situation changes.
- The DCWs need to be involved in the holistic planning of care and symptom management and maintaining comfort and well-being; at present DCWs are tasked to deliver specific aspects of care. They are sometimes not privy to information around medical history and plans, such as do not attempt resuscitation orders. If a care worker understands the greater picture then decisions and support are more meaningful for the worker as they talk to the person.
- Person centred thinking allows a framework for the DCW to develop competency as they listen more closely to the person and understand what is important to them and their families.

Sources of this insight for competences

- Focus groups of family and carers of people who had recently died.
- Domiciliary care workers questionnaires in Wakefield and evaluation of practice in Hull.
- The use of person centred tools in practice (people, GP, practice managers).
- Stories captured on film as input to the competency work (people, domiciliary care workers, family carers, social care managers).

4.3 Integrated care and trigger points

One of the aims within this project was to articulate the core competences required at front end/trigger points. As stated earlier in this report, the ‘trigger points’ for someone approaching end of life may be subtle changes in the physical, social or medical need of the person, and through working daily with people, the DCWs, we believe, are ideally placed to ‘flag’ changes and work in a multi-partnership approach to improve the person’s life.

It has long been recognised that support for people at end of life is better when it is part of a multi-disciplinary approach that includes the person and their family within that decision making process. Health systems use the Gold Standards Framework to co-ordinate partnership working but how well this has translated to social care still seems to be problematic. There was mixed understanding by DCWs as to what a Gold Standards meeting was but a general consensus that if it helped the person, then their involvement would be a good thing.

Below are some, but not exhaustive examples of trigger points that we have seen that may indicate the DCW as part of a multi-agency approach could improve well-being and outcomes for people.

Examples of front end/trigger points of people approaching end of life for domiciliary care workers

- start of continuing health care funding
- admissions to hospital
- changes in usual behaviour (‘not themselves’ scenario)
- verbalised concern by person and their family
- diagnosis of long term condition and symptomatic control.

Integrated care: summary of findings

- Professions still work in silos, knowledge of each other’s processes to support people at end of life are still not clear to workers caring day to day for people.
- Examples of where health and social care work together improve the perceived care by people at end of life.
- DCWs see end of life care as part of their job, being part of multi-agency support to a person at end of life is considered as a positive thing as it benefits the person.

Integrated care: what aspects of an integrated care pathway were demonstrated and worked well.

We have found evidence from informal carers/relatives that the support they need from hospital and health services is lacking in respects to understanding information and knowing what the next steps are. The process of communication and feeling respected within a system is crucial to people as they deal with difficult emotions and physical symptoms and is expressed as paramount to them feeling supported.

Pockets of integrated practice seen within this project outlined a greater satisfaction by people, their spouses and the carers when health and social care worked together to understand the needs of the person.

Using person centred thinking tools ‘what is working and not working in my life and what do I want to change?’ it was identified that one lady’s GP always gives her time to sit and talk, she asks her how she feels and listens to any thoughts on what might make her feel better, and that supports the lady well. Similarly, it emerged using the second of the two tools mentioned here that good support for her means giving “Reassurance around her breathing, [as] she becomes very frightened when she struggles to breathe. Sit and talk with her. Know that she needs to be given time to speak, she may become very anxious. Talk to her reassuringly and she will tell you what she wants to say.” This gives clear instructions to both health and social care staff regarding how best to support her, particularly when she becomes distressed, and was something that both the health and social care workers involved in her care were able to commit to doing.

We also have some evidence of what happens when agencies continue to work in silos.

In using the “What is working and not working in my life and what do I want to change?” tool with one lady highlighted that her anxiety is heightened by “health professionals not returning calls”, when her expectations of her care do not match what she receives; “Not having my blood pressure taken fortnightly which is a real worry to me” and the “District nurse talking to me about other people she has been visiting who are dying”, which M finds very upsetting. Although her DCW was then able to use the “What is important to me now and how do I want to be supported?” to understand how she could be better supported and that best support is having options talked through with her and for staff to listen to her concerns, it was clear that no such care or support was currently being provided. This meant that for her, the service she received was perceived by her to be sub-standard.

Learning from people at the end of life

Two participants in Hull both expressed a level of anxiety and worry associated with their health, but although this was acknowledged by the DCW and medical staff supporting one lady, one of the ladies felt her concerns were left unattended by the district nurses who care for her.

A lady with dementia and her husband feel supported by the DCW, however they do not feel supported when it comes to preventing unnecessary admissions to hospital which she and her husband find distressing. Her anxiety increases due to being around people she doesn't know, poor discharges and long waits for transport in the middle of the night.

'No consistency in care provider – different people attended our home'

'We didn't understand what happened next, lack of information about services and treatment'

Learning from those who support people at the end of life

'Integrated care can take place in day-to-day practice: None of the team is involved in Gold Standards meetings at the moment. Staff tend to work in their own bubble, not enough communication between caring staff and nursing'.

It would be good to speak to carers direct regarding what needs doing for the patient i.e. 'to place client in chair in a certain way'. It is better when paths crossed between carer and district nurse at end of life, it really worked well as we were all there at the same time, relationships were then formed with family and district nurse.

There are missed opportunities by health staff to understand issues around care for people by asking social care staff. The current practice for support for adults with learning disabilities in Calderdale is relevant. A risk/dependency assessment is conducted to identify the full range of needs/risks and support them whilst a person is in hospital using care workers, family and friends.

Sources of this insight for integrated pathway

- focus groups of family and carers of people who had recently died
- domiciliary care workers questionnaires in Wakefield and evaluation of practice in Hull
- the use of person-centred tools in practice (people, GP, practice managers).

5. Key worker competency findings

We have produced a framework which maps the competences we found during the project against the ‘Common Core Competences and principles for health and social care workers working with adults at the end of life’ framework produced by NHS National End of Life Care Programme, Skills for Health, Skills for Care and the Department of Health. Also described in this framework are the National Occupational Standards which support the competences at assistant level (groups B and C) which is applicable for health and social care staff who are generally not statutorily regulated.

KEY WORKER COMPETENCIES FINDINGS FRAMEWORK

Group B:	Staff who frequently deal with end of life care as part of their role
Minimum skill and knowledge level	need to be enabled to develop or apply existing skills and knowledge to the principles and competencies. May require additional specialist training
Group C :	Staff working within other services who are involved with end of life care infrequently
Minimum skill and knowledge level	Good basic grounding in the principles and competencies; alongside knowledge of where to seek expert advice or refer on to

National Occupational Standards for Assistant level staff (generally not statutorily regulated)					
	HSC21	EUSC02, HSC398, GEN75	HSC24, HSC227, HSC216, HSC218, HSC219, HSC225	HSC328/AG2	HSC23, HSC26, HSC3116
Competence Dimension	Communication Skills	Assessment and Care Planning	Symptom Management (maintaining comfort and well being)	Advance Care Planning	Overarching Values and Knowledge
a	✓	✓	✓	✓	✓
b	✓	✓	✓		✓
c	✓	✓	✓		
d		✓	✓		
e	✓	✓	✓	✓	✓
f			✓	✓	
g					

Common core competences and principles for health and social care workers working with adults at the end of life –
NHS National End of Life Care Programme/Skills for Health/Skills for Care/Department of Health

In answer to the overarching question of could or should domiciliary care workers function as key workers we have mapped the competency findings from the project against five elements which have been distilled from the NICE definition of a key worker. This mapping suggests that there are domiciliary care workers with the appropriate competences to fulfil the key worker responsibilities.

Earlier in this report we considered the competences that would be needed for a domiciliary care worker to operate as a key worker. In this section we explain the competences we found in practice. This is shown in the table on the next page and is followed by an independent evaluation using the film of Real stories: Real insight explained in the methods section earlier in our report.

The competences in evidence

Earlier in this report we explained the definition of a key worker and the 29 Common Core Competences for end of life care. 21 of the 29 competences required for a DCW to function as a key worker were in evidence on the film. These covered communications (4), assessment and care planning (5), symptom management (6), advance care planning (3) overarching values and knowledge (3).

Table 2: Key worker role to show the competences that were in evidence (17 of the required competences plus 4 competences over and above).

Common Core Competences		1. Communications skills	2. Assessment and care planning	3. Symptom management	4. Advance care planning	5. Overarching values and knowledge
Definition of key workers (Health and Social Care)	Co-ordinating person's care	a, c	c, d	b, e, f	e, f	a
	Promoting continuity	b, e	e	a, c, e	a	a, b
	Empowering the person	b	b, c, d	b, e	e, f	a, b
	Signposting	a a	d --	a		
	Effective team member	e c	e, f f	a, e		

Independent view

Skills for Health was originally commissioned to map “stories” on end of life care pathway experiences to the Common Core Competences and principles for health and social care workers also underpinning the National Occupational Standards.

The aim of this work was to directly relate competences and National Occupational Standards to real life experiences and thereby articulate competences in a way that service users can fully understand.

In the event the competence and National Occupational Standard mapping utilised almost seven hours of “raw” footage as opposed to the individual “stories” as originally envisaged. Nevertheless, it has still been possible to directly relate competences and National Occupational Standards to real life experiences and thereby articulate competences in a way that service users can fully understand in accordance with the original agreed proposal.

Findings

The findings fall into two groups - general and specific.

The general findings are:

Throughout the seven hours of film what was very clear was the real evidence that competent “social care” was being delivered by a caring, compassionate and highly skilled professional social care workforce who universally worked hard to ensure that the care being delivered was person centred. The commission for the work we were asked to undertake was to identify when appropriate “end of life competences” were being delivered or were required and therefore the mapping of the far broader health and social care National Occupational Standards was out with the scope of our work. It is useful to note that should this type of work be required at a later date, the current filming will provide a highly effective evidence base.

It was also noticeable from the filming that as people are living into their 90s their immediate family members i.e. sons and daughters are often in their 70s and have health issues themselves. This is accentuated when someone’s primary carer is their spouse. Grandchildren are often in their 40s with large family commitments and therefore lack the time to actively support the primary carer. As our population ages the ability of family members to undertake care is going to be increasingly impacted by their own health issues or family commitments. This will impact on how care for people in their final years and months is delivered in the future.

In addition to the filming we were also supplied with very helpful “Director’s Notes”. In terms of competence mapping there was some rich material where wonderful care was being provided.

In some of the footage the interviews with service managers whilst providing very rich evidence of what motivates someone to work in a social care setting and what are the underpinning “soft competences” (capabilities) it didn’t provide the necessary evidence to map “end of life competences”.

In order to be an effective care worker you need to be capable and competent, not just competent. Capability is usually inherent whereas competence can be acquired through training and when combined with innate capability really produces a highly skilled and very professional care worker as evidenced throughout almost all the filming. This is borne out by the fact that of the forty five competence references only eight were instances where competence appeared to have not been displayed or were perhaps lacking. Of these eight instances only half were in respect of social care provision with the other half relating to healthcare provision.

In terms of the type of Common Core Competences either exhibited by staff or required the data is as follows:

Communication skills	9
Assessment and care planning	9
Symptom management, maintaining comfort and well-being	4
Advance care planning	3
Overarching values and knowledge	10

The specific findings in the mapping are outlined in the full report where individual instances in the filming are mapped to the detailed competency definitions included earlier in this report.

Key messages from the competency mapping:

- When mapping the definition of key worker against the Common Core Competences for end of life care, we found evidence of 72% (21 of 29) of the competences required in supporting people in end of life care already taking place in practice.
- In order to be an effective care worker you need to be capable and competent, not just competent. Capability is usually inherent whereas competence can be acquired through training and when combined with innate capability really produces a highly skilled and very professional care worker.
- Assistant level care and support is provided by care workers similar to the assistant level of care a person would receive within a hospice or specialist unit.

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