

# Patients' and carers' views on dementia workforce skills

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## Abstract

**Purpose** – *Through consultation with people living with dementia and carers, this paper aims to identify skills that patients and carers feel need to be developed in the workforce. This work is part of a project to develop competencies for the West Midlands dementia workforce.*

**Design/methodology/approach** – *People living with a dementia and carers were contacted through cafés, a carers' group and memory group, and two people contributed interviews to the analysis. All materials were analysed qualitatively using thematic analysis.*

**Findings** – *Feedback was received from 69 individuals. In total, six major themes were identified: knowledge about dementia, person centred care, communication, relationships, support and helping people engage in activities.*

**Originality/value** – *It is argued that people living with dementia and carers bring unique and valuable perspectives to an analysis of the skills of the dementia workforce, which grounds the required skills in the relationship between the worker and the person and family they are working with. This different emphasis needs to be considered and addressed throughout dementia training and education.*

**Keywords** *Competences, Dementia workforce, Dementia training, Person-centred care, Relationship-centred care, Users, Carers*

**Paper type** *Research paper*

## Background

As the population ages (Alzheimer's Society, 2007), dementia has become a growing challenge for services and a growing expense for the health and social care system (Alzheimer's Research Trust, 2010). The National Dementia Strategy (Department of Health, 2009) set out, in objective 13, the need for "an informed and effective workforce for people with dementia" (p. 13), elaborating on it thus:

[...] people with dementia and their carers need to be supported and cared for by a trained workforce, with the right knowledge, skills and understanding of dementia to offer the best quality care and support (p. 66).

In the West Midlands, it had been stated even before the publication of the National Dementia Strategy that minimum core standards of competency for Dementia care would be used to underpin education programmes for those working in the care of people with dementia (Saad *et al.*, 2008).

Although objective 13 and a dementia core competency framework might seem to be clear and simple, it is far from straight forward in practice. For example, what do we mean by "the dementia workforce"? The "dementia workforce" is itself a complex concept and could include the vast majority of staff working in physical healthcare, mental healthcare, residential and nursing care and social care. Much of the care of people with dementia is carried out by untrained carers and it could be argued that influencing their knowledge, skills and understanding might have a great impact on care, but would be a huge challenge. The policy

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of personal budgets in social care (HM Government, 2007) may remove more care from the remit of trained staff to that of untrained carers including relatives (Benbow and Kingston, 2010). Similarly, what is “right” or appropriate in terms of knowledge, skills and understanding? Indeed, how do we know what is “right”, and who decides what is “right”?

The work described in this paper starts to address the issue of what skills, knowledge and understanding are needed by members of the dementia workforce, by investigating people living with a dementia and carers’ views of what is needed by those working with them. There is evidence that the people living with a dementia and carers value aspects of care which may differ from those most highly valued by staff: good or bad experiences of care are described more in terms of relational aspects rather than technical aspects of care (Bridges *et al.*, 2010). The need to balance training between intellectual and theoretical analysis and an understanding of human experience has been flagged up in relation to training health professionals (Pew-Fetzer Task Force on Advancing Psychosocial Health Education, 1994), but is equally relevant to social care professionals.

We consulted with people living with a dementia and carers living with dementia as part of a regional project aimed at developing competencies for the West Midlands dementia workforce. For further details of the competency framework project see Tsaroucha *et al.* (2010). The aim of the consultation reported here was to identify the skills which people living with a dementia and carers felt needed to be developed in the health and social care workforce.

## Method

As part of a project to develop core competencies for the dementia workforce and to map dementia training across the West Midlands (Tsaroucha *et al.*, 2010), we consulted with people living with dementia and carers to investigate their views of the skills needed by the health and social care workforce in working with families living with a dementia. We identified four areas of interest:

1. What skills do you value in people from health and social care working with you?
2. What skills have you found missing in people from health and social care working with you?
3. What have you found workers in health and social care do well?
4. What have you found workers in health and social care do badly?

We approached people with dementia and carers of people living with dementia through Approach North Staffordshire, which runs a number of local cafés, and the Alzheimer’s Society. A member of the team attended two cafés, one Carers’ Group and one Memory Group, introduced the overall project and sought feedback in one of two ways, verbally or on feedback sheets which set out the questions above and also listed our draft of eight core competencies which we were then working on (Table I). In order to maximise flexibility and informality, those people who chose to give verbal feedback to the researcher could opt to do so individually or in a group. We decided not to ask the café consultees whether they were people living with dementia or carers in order to avoid labelling them. Following the consultation two people living with a dementia agreed to be interviewed to give their views of the skills needed in the dementia workforce for teaching purposes. They subsequently agreed that the content of their tapes could be included in our analysis of workforce skills.

Feedback was received from 69 individuals as part of the consultation process and two service users subsequently contributed interviews to the analysis. Of the 69 individuals, 11 were people living with a dementia, 11 were Carers’ Group members and the remaining 47 (29 from one café, 18 from a second) were café attenders, who were mostly (but not exclusively) carers. Some of the feedback was given in written form; other feedback was taken as contemporaneous notes of conversations. This written material plus the two audiotaped interviews were analysed qualitatively using NVIVO (Bazeley, 2007; QSR International, 2011).

**Table 1** Core competencies as distributed to people living with a dementia and carers as part of the consultation process

*We have produced a list of core competencies – these are the main areas where members of the workforce need skills to work with people who are living with a dementia and their families. Here are the eight main areas. If you have any thoughts or ideas about which are most important to you or whether anything is missing please let us know*

- 1 Knowledge/Awareness of Dementia
- 2 Person Centred Care
- 3 Interaction with people living with a dementia
- 4 Interaction with carers/families
- 5 Enriching the life of individuals with dementia
- 6 Understanding the behaviours of individuals with dementia
- 7 Dementia worker self-care
- 8 Promoting best practice

## Results

We identified six key themes from the consultation with people living with a dementia and carers that related specifically to workforce skills. These are; in no particular order:

1. knowledge about dementia;
2. person centred care;
3. communication;
4. relationships;
5. support; and
6. helping people engage in activities.

### *Knowledge about dementia*

Respondents highlighted the need for more knowledge amongst staff working with people with dementia, e.g.:

[...] people don't know enough about Alzheimers disease and don't understand the condition.

The point was made that it needs to be applied knowledge not just theoretical knowledge:

[...] a book can only tell them so much. Face to face contact as well as the book knowledge and dealing with the everyday problems of people that live with dementia all the time can give them experience, anyway it's dealing with people – people that are in difficult and traumatic situations because – like I say – it's a devastating illness to have thrust upon you;

and:

[...] marry the theory you learn with the reality of dementia care. Realise that something that appears trivial can make a huge difference to the quality and life a user and their carer can have.

In addition the knowledge needs to be communicated to people living with dementia to avoid marginalising them:

[...] they also don't give the person with dementia enough information – maybe they don't expect them to understand?

and perhaps service users and carers may need different information at different times:

I think the information side is more important for carers – the information they're given should be slightly different to what the patient's given.

### *Person centred care*

Both people living with dementia and carers reported that many staff did not tailor care offered to the individual and family receiving care. They felt that services had a checklist of

services into which families and their assessed needs were fitted, and that changes in staff did not help the development of a relationship between a person with dementia and those staff members involved in their care. Two quotations illustrate carers' thoughts on person centred care:

[ . . . ] ability to think about things from the point of view of the person with dementia and their family carers.

[ . . . ] recognising that she's a person. She was somebody's wife – she's somebody's mother.

This was an area that people living with a dementia also felt very strongly about:

[ . . . ] every person is different but you've got to be able to have sufficient knowledge of what you're dealing with to approach each person and to be able to listen and to tell them and reassure them what this illness is and what it's all about.

[ . . . ] respect individual needs – not everyone makes standard choices.

[ . . . ] anyone in any caring system must guard against forgetting that we are human beings first and foremost and we merit the dignity and respect they would expect for themselves.

[ . . . ] if only health and social care would realise sending different care workers at different times only causes users insecurity and distress.

Carers also highlighted the effects of:

[ . . . ] continual change of caring staff which unsettles both members of staff and people living with a dementia.

### *Communication*

Many of our respondents raised the issue of having the opportunity to talk with someone about their fears, hopes and challenges. The focus of care is seen as practicalities of daily life rather than the emotional and psychological difficulties that accompany living with a dementia. Communication includes communication with families and with people living with dementia:

[ . . . ] ones that have seen me as an individual with individual needs, given me hope, given me truthful answers, most of all they have listened to me, really listened to me not fobbed me off with meaningless platitudes, listened to my fears, let me drop the front of being brave, seeing beyond what I was asking. One of the most important things to a user is to be able to talk, really talk, our worries, our fears;

[ . . . ] people must have someone they can talk to and to give them information but somebody they can talk to if they have any problems", and communication with carers: "listening to carers and believing them.

Another aspect raised is that of communication across individual professionals, within and between agencies:

I wish health and social care departments would communicate with each other which would bring the consistency users need into focus. My pet wish is that health and social care wouldn't scatter their talk with abbreviations such as CPN, PCT, etc. it leaves us bewildered as to what they mean and while we struggle to puzzle it out we've missed the rest of what's been said.

Our respondents did not perceive their care as integrated and reported that their experience was that information is not shared across agencies or even between professional groups within an agency.

### *Relationships*

People living with a dementia highlighted the need for a more positive personal relationship with those caring for them, observing:

[ . . . ] there's not a lot of warmth there,

or:

[ . . . ] health and social care workers, some of whom, I've found, seem to hold themselves aloof from any sort of warmth or personal involvement with you. Are they afraid of failing the system yet not afraid of failing you?

and:

[...] how we wish for consistency in our care plan, where we can build up trust, maybe make a friendship with our care-workers.

Again this linked in with the focus amongst staff being on the practicalities of care and time constraints rather than on the person and the family as individuals.

Carers noted the need for people:

[...] to feel loved and cared for,

observing that:

[...] people who get to know you understand more.

It was evident that both people living with a dementia and carers shared a wealth of knowledge about staff, they perceived as “good” at their job. These were the people who “went the extra mile” and would deal with things that other staff regarded as outside their remit. They were perceived as more caring and more committed.

### ***Support***

The need for support was highlighted primarily by people living with a dementia in relation to their own needs. One said:

[...] these sort of things cause the fear and it's being isolated with them fears with no one to turn to;

and:

[...] it would have been nice to have had someone to confide in, other than the person that's looking after me.

People living with a dementia also felt that carers needed more support, saying:

[...] give carers chance to unload.

The inadequacy of follow up offered by services in addressing the isolation of both carers and people living with a dementia was emphasised by both groups.

### ***Helping people engage in activities***

This theme was primarily raised by people living with dementia, who talked about “keeping the brain active” and “keeping your interests going”. They distinguished between established activities/interests, e.g.:

[...] help you to keep doing the things you can do, e.g. X likes cycling, does dementia have to stop him cycling?

and trying new things, noting that just because a person has a dementia they “don't want life to be boring”. Another patient commented that they wanted:

[...] to be given the chance to have a life albeit different to what we expected,

alluding to a desire to carry on doing things even though they might be different from the ones she would have chosen to be involved in before her illness.

### **Discussion**

Undoubtedly our respondents were commenting on the system as they experienced it rather than skills and competencies in the way that they are understood by trainers and educators. In addition, the patients and carers who contributed to this work were not recruited in such a way as to be representative, and the care delivered by members of the dementia workforce depends greatly on the systems set up to deliver it which place constraints on how it is delivered in practice. Although these could be regarded as limitations of the study, they do not detract from our respondents' acute observations of what staff members were good at and what they struggled with, and there was considerable agreement amongst our

respondents. Both people with dementia and their family members could distinguish between staff who merely dealt with the practicalities of care and those who gave of themselves in caring about the people they worked with and relating to them as people. People living with a dementia and their carers bring a unique and valuable perspective to an analysis of the skills of the dementia workforce, which grounds the required skills in the relationship between the health or social care worker and the person and family they are working with. This different emphasis needs to be considered and addressed throughout training and education of both professional and untrained staff working in dementia care. It also underlines the importance of involving people living with a dementia and carers, including those living with a dementia, in education at all levels (Tew *et al.*, 2004).

This consultation supported the core competency framework developed in our Care Pathway project for the West Midlands Strategic Health Authority (Tsaroucha *et al.*, 2010) and Table II sets out some ways in which the core competencies and the patient/carer themes interlink. The two core competencies which are least prominent in the patient and carer feedback are “dementia worker self-care” and promoting best practice.

The latter competency may be seen in organisational terms and may sometimes conflict with person-centred care. An example of this conflict is demonstrated by the NICE guidance on the use of the anti-Alzheimer’s drugs published in 2006, which stated that the drugs were not cost effective for use in people with early Alzheimer’s disease and that they, therefore, should not be used in the NHS for this group of people: this guidance has now been revised (National Institute for Health and Clinical Excellence, 2011). It could be argued that the original advice ran counter to individualised person-centred care since the drugs had been shown to be clinically effective, as was acknowledged in the previous guidance.

The concept of “dementia worker self-care” (Tsaroucha *et al.*, 2011) has been described as including skills such as identifying one’s feelings, beliefs and/or attitudes which may impact on relationships with families living with a dementia; being aware of and taking action to minimise or prevent burnout and stress; seeking appropriate support and continuing professional development opportunities and awareness of personal safety issues. These skills are likely to be neglected and under-emphasised in dementia training. They relate to the

**Table II** Suggested relationships between core competencies and patient and carer themes

	<i>Core competency</i>	<i>Patient/carer themes</i>	<i>Comments</i>
1	Knowledge/awareness of dementia	Knowledge about dementia	Need to balance book knowledge with a knowledge of the effect on families (emotional awareness)
2	Person centred care	Person-centred care Helping people engage in activities	All the patient and carer themes are relevant to person centred care but these two are perhaps the most important
3	Interaction with people living with a dementia	Communication Relationships Support	Communication underlies interaction with people living with a dementia but so do relationships and these translate into support
4	Interaction with carers/families	Communication Relationships Support	Similarly, communication underlies interaction with carers and families but so do relationships and these translate into support
5	Enriching the life of individuals with dementia	Helping people engage in activities Person-centred care	All the themes contribute to enriching a person’s life but the two listed here are perhaps critically important
6	Understanding the behaviours of individuals with dementia	Knowledge about dementia Person-centred care Communication	Knowledge about dementia needs to be related to the individual circumstances of the person and family living with it
7	Dementia worker self care		This was not addressed in the patient/ carer feedback
8	Promoting best practice		Best practice is often considered at an organisational level but needs to be equally powerful at an individual level where it links with person-centred care

patient/carer theme of relationships. It is interesting to note that the concept of depersonalisation in the Maslach Burnout Inventory (Maslach *et al.*, 1996) involves withdrawing from close relationships between professionals and the people they work with (relationships which are highly valued by people living with a dementia and their carers) into a distanced mechanistic role.

Thus, it is important not only that people living with dementia and their carers are involved in education and training of the dementia workforce (Benbow and Boyce, 2008), but that they are involved in ensuring that curricula and training programmes incorporate those aspects of care which they value and that relational aspects of care are not sacrificed in favour of technical and scientific knowledge and skills. It is also important to recognise that the dementia workforce is a broad concept and should be understood to include physical healthcare settings which provide treatment for people with dementia who need treatment by reason of physical illness: there is evidence that people in this situation do better if their mental health needs are appropriately addressed (Royal College of Psychiatrists, 2005).

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