

**“Talking about my experiences ... at times disturbing  
yet positive”: producing narratives with people living  
with dementia**

**Susan Mary Benbow**

University of Chester, UK

and

**Paul Kingston**

University of Chester, UK

**Correspondence address for corresponding author**

Prof SM Benbow, Centre for Ageing Studies, Faculty of Health and Social  
Care, Riverside Campus, Chester CH1 1SL.

Email: [drsmbenbow@gmail.com](mailto:drsmbenbow@gmail.com)

Mobile: 07789 485435

## **Abstract**

**Background:** This research investigated narrative production and use with families living with dementia. We hypothesised that the process of narrative production would be beneficial to people with dementia and carers; and would elicit important learning for health and social care professionals.

**Method:** Through third sector partners, we recruited community-dwelling people with dementia and carers who consented to develop written, audiotaped or videotaped narratives. Audio-taped narratives were transcribed verbatim and handwritten narratives word-processed. After checking by participants, completed narratives were analysed thematically using qualitative data analysis computer software. A summary of the analysis was circulated to participants, inviting feedback: the analysis was then reviewed. A feedback questionnaire was subsequently circulated to participants, and responses were analysed thematically.

**Results:** Twenty-one carers and twenty people with dementia participated in the project. Four themes of support were identified: 'relationships', 'services', 'prior experience of coping' and having an 'explanation for the dementia'. Three themes were identified as possible additional stresses: 'emotions', 'physical health' and 'identity'. We suggest a model incorporating all these themes, which appeared to contribute to three further themes; 'experience of dementia', 'approaches to coping' and 'looking to the future'.

In participant feedback the main themes identified were 'emotions', 'putting things in perspective', 'sharing or not sharing the narrative' and 'actions resulting'.

**Conclusions:** Producing a narrative is a valuable and engaging experience for people with dementia and carers, and is likely to contribute to the quality of dementia care. Further research is needed to establish how narrative production could be incorporated into routine practice.

**Keywords**

Carer, dementia, living with dementia, narratives, relationships.

*Prepublication draft*

## Introduction

The historical power dynamic between the public and professionals is experiencing a paradigm shift in the United Kingdom (UK). There are several reasons for this: the development of new technologies that can speedily share medical knowledge with the public, the emergence of significant failures in professional health care (Davies, 1993; Sibbald, 2001) and systemic catastrophes in healthcare (Francis, 2013) which have led to the development of public concern about healthcare professionals' and organisational competence and the creation of pressure groups (eg Save the NHS). In response governments and learned societies from health and social care professions are now enacting changes in policy:

*'The Government's ambition is to achieve healthcare outcomes that are among the best in the world. This can only be realised by involving patients fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone'. (Department of Health, 2010, p. 13)*

It is only relatively recently (perhaps the last ten years in the UK) that the narrative has been considered as one of various lenses through which a health condition may be viewed, and the significance of narratives has become recognised. The importance of learning from service users' narratives has been acknowledged in the Expert Patient (sic) Programme (NHS choices, 2013). More recently Berwick Report recommended that:

*'All organisations should seek out the patient and carer voice as an essential asset in monitoring the safety and quality of care.'* (National Advisory Group on the Safety of Patients in England, 2013, p. 5)

'Patient experience' was also a key theme identified as a foundation of quality care in the Keogh Review (Keogh, 2013).

At the same time health professions are challenging the dominating mantra of 'evidence based healthcare' that emerged to control practice in the early 1980s. We would argue that evidence (science) has, and will, continue to be a driving force for improved healthcare; as Vannatta and Vannatta (2013) eloquently argue, this is not for debate:

*'The application of the scientific method in its proper context of disinterestedness is almost entirely beyond contestation'*. (Vannatta & Vannatta, 2013, p. 36)

However, alongside this, there is also a desire to develop a more balanced evidence base that consists of empirical studies alongside the experience of service users:

*'The means of modern medicine lacks a metric for existential qualities such as the inner hurt, despair, hope, grief, and moral pain that frequently accompany, and often indeed constitute, the illnesses from which people suffer'*. (Vannatta & Vannatta, 2013, p. 37)

It is therefore not surprising that the literature on narratives in medicine has been growing increasingly compelling over about the last twenty years (Divinsky, 2007; Greenhalgh & Hurwitz, 1998) and narrative has become a

legitimate area of study for health care practitioners. Greenhalgh and Hurwitz note that, although we might emphasise to health care staff the importance of taking a history, curricula rarely acknowledge the skills of:

*'listening to, appreciating and interpreting patients' stories'* (Greenhalgh & Hurwitz, 1998, p. 12)

Oral narratives are developed in conversation, that is, in relationship to others, and could be regarded as an integral part of relationship centred approaches to care (Bridges, Flatley, & Meyer, 2010). One way to understand narratives is as structured accounts of events across time, which can be examined, negotiated, changed and act as agents of change. They are created and shared through language, either in writing or verbally, and are part of how we all make sense of our lives (Cole & Knowles, 2001b; Elwyn & Gwyn, 1998; Samuel & Thompson, 1990). They also offer a means of addressing existential issues (Greenhalgh & Hurwitz, 1999). In telling and retelling stories old meanings develop and evolve, and new meanings emerge (Anderson, 2007; Monk & Gehart, 2003). This happens through the course of a chronic illness like dementia: Skultans said that:

*'narrative introduces new possibilities in a life narrowed down by illness'* and *'narratives facilitate the search for, and construction of, new meanings in situations where the old meanings no longer work'*

(Skultans, 1998, pp. 228 & 232)

Producing a narrative is an art rather than a science (Drife, 1998) and can be regarded as complementary to a more traditional scientific approach. There

are three different although overlapping areas where narrative might contribute to healthcare (Kalitzkus & Matthiessen, 2009):

1. In research and training contributing service users' perspective.
2. In medical practice, offering broader experiential understanding to medical knowledge, and physician-family relations.
3. In evidence based medicine providing an additional complementary source of knowledge, which addresses experience and subjectivity, beyond the 'gold standard' of randomized controlled trials.

One of us (SMB) has been involved in a project which employed narratives as a means of sharing the experiences of carers of older adults with dementia within a group setting (Benbow, Ong, Black, & Garner, 2010): narrative production was reported to be therapeutic for the carers who produced them.

This project aimed to build on previous work by investigating how narratives can be produced and used by families living with a dementia. We hypothesised that the process of narrative production would be beneficial to both people living with a dementia illness and family carers; and would lead to learning about their experiences. In this paper we use the term person/people/ individual with dementia for people who are living with an illness that has been given a diagnosis of dementia; carer for the family carers of people with dementia; participants to encompass both groups, and service users to describe people with dementia and carers who are using dementia services (Simmons, Hawley, Gale, & Sivakumaran, 2010).

## Method

This project was given ethical approval by Staffordshire University Faculty of Health/ Faculty of Sciences Ethics Panel. In partnership with three organisations, Approach (which provides dementia support services in Staffordshire), Accord Housing, and a branch of the UK Alzheimer's Society, we recruited community-dwelling people living with a dementia and family carers of people living with a dementia who were prepared to develop personal narratives of their journeys with dementia. All those involved gave their informed consent. Participants were given the choice of preparing a written, audiotaped or videotaped narrative. The process of speaking the narrative was started using a grand tour question (Cole & Knowles, 2001a; Westby, 1990):

'I would like you to tell me the story of your life with dementia. The best way to do this is to start from the time that you first became aware that you (or your relative) might have dementia. Tell me all the things that happened one after the other until today. Please take your time and give details. Everything is of interest that is important to you.'

The grand tour question was sent to participants in writing in advance and it was suggested that they might wish to think about three additional questions, before meeting the researcher:

1. how has living with dementia affected your life and the lives of family members?

2. what has helped you cope in your journey with dementia?
3. what would you or your relative have liked to do differently?

The additional questions were not asked formally during the interview. People spoke at length in response to the grand tour question in a free flowing narrative, and the role of the researcher was to facilitate and encourage them, asking clarifying questions when appropriate. Participants could refer to notes prepared beforehand to help them remember what they wanted to include, if they so wished. After a break participants were asked if they wished to add anything more to the narrative.

All audiotaped narratives were transcribed verbatim, and returned to the participants who could correct/ change them as they wished. Handwritten narratives were typed up and returned to participants for checking.

The completed narratives were analysed thematically using NVivo, a qualitative data analysis computer software package (Bazeley, 2007; QSR International, 2011): one author coded the transcripts and texts thematically by reading and re-reading the source material in order to identify themes. Themes and text coded to themes were reviewed, discussed, modified and developed by both authors. Once agreement had been reached, a short summary of the analysis was prepared and circulated to participants with an invitation for further comments and feedback. The analysis was reviewed in response to feedback received.

A feedback questionnaire was then circulated to participants with an invitation to 'give us some feedback about putting together your journey and tell us whether anything has resulted from it.' Participants could respond in any of four ways: by completing the questionnaire, in conversation over the telephone, by email, or by attending one of a series of cafés attended by a team member and speaking with them face to face.

The feedback received was analysed thematically using NVIVO.

## Results

We recruited 21 carers and 20 people with dementia to the project. Table 1 gives demographic information about the participants. All the people with dementia chose to make audiotapes in conversation with one of the researchers. Two carers wrote their own narratives, and the remaining carers' interviews were audiotaped. Five couples chose to be interviewed jointly; one couple opted to be interviewed separately. In summary there were: 15 carer stories (2 handwritten); 6 couples stories; 14 stories of people with dementia: giving a total of 35 narratives from 41 individuals. The longest story was transcribed into a manuscript of over 12000 words: the shortest was about 1500 words.

The themes identified in the qualitative analysis are listed in Table 2. We identified four themes of support to people with dementia and family carers. The two main ones are 'relationships' and 'services'. Two additional possible supports are 'prior experience of coping' and having an 'explanation for the

dementia'. Three themes were identified as possible exacerbating factors or additional stresses, in terms of complicating life with a dementia: these are 'emotions', 'physical health' and 'identity'. All these themes influence the outcome themes: 'experience of dementia', 'approaches to coping' and 'looking to the future'. The themes and subthemes are explained below and illustrated with quotations in Table 2.

### ***Supportive themes***

'Relationships' included spousal, family and social relationships. People with dementia commonly stressed the importance of their partner in helping them communicate. For carers the reaction of their partner to them could be affirming, but for other carers, whose partners could no longer reliably recognise them, their partner's reaction could be distressing. Participants spoke positively about the support that they had from their families, especially children and grandchildren. Carers commented on the support they received from family members who lived nearby, but occasionally noted how hard it was for family members living at a greater distance who could not be closely involved. Often there was one family member who provided most of the support. Couples without children spoke about how they missed this potential source of support. Individuals noted difficulty in reciprocating with support for other family members.

Carers described changes in their social life. Several people described support from neighbours and/or friends, who provided regular practical help (examples given included people from church and from the golf club). One

person with dementia pointed out that she now found groups difficult, but could still meet with friends on a one-to-one and enjoyed their company and conversation.

Many 'services' were mentioned: the ones listed in Table 2 are those mentioned most commonly. GPs generally had provided good support and prompt referrals. They were described in a series of positive adjectives (see Table 2). One of the main service problems noted was the long period of time to get investigations carried out (as one person with dementia described it - *time we don't really have*), and the fact that the focus was on tests/ questions/ puzzles and not on the matters worrying the family. Both carers and people with dementia talked positively about the support that they had received from third sector organisations, which included a wide variety of services such as sitting services, carers groups, memory groups for people living with dementia, cafes, information packs. People from these organisations were often mentioned by name and the relationship with them was clearly valued. Day care and respite care were more often mentioned as a negative experience for the person with dementia, although carers might value the break. Experience of social services was similarly mixed. Many people spoke warmly about their social worker and the help they organised, but contacting social services and perceived pressure to discontinue involvement had been a problem for a number of people. Money and managing finances was another area of difficulty and for this reason was coded separately. Carers who had organised direct payments, felt they had worked out well, although there had often been delay in getting the payments established.

Most narratives mentioned an 'explanation for the dementia' and some more than one. 'We all forget' or 'it's just my/her/his age' was a common explanation. One woman had thought initially her illness was related to the menopause. Brain damage/ brain degeneration was offered as another possible explanation. One carer described the illness as an age-related degeneration. Some carers could suggest no explanation (it didn't make sense), and others described the illness in terms of going back to childhood. One referred to another relative who understood dementia in terms of the person becoming 'stupid'. Other possible explanations were: an act of God, playing football with a hard ball, and stress. Some explanations led to the assumption that nothing could be done, others (particularly the brain damage hypothesis) were put forward as suggesting ways of helping deal with illness-related difficulties and seemed to offer hope and support, in that continuing to be active might help the brain find different routes for information to flow down.

'Prior experience of caring' was cited in terms of giving a person experience in, or understanding of, caring. Sometimes it involved experience of caring for someone with dementia; others described experience of caring for one or more family members with a terminal or long-term illness as relevant to their current situation.

### ***Exacerbating themes***

Three themes captured factors likely to exacerbate the difficulties of living with dementia. These are 'emotions'; 'physical health'; and 'identity'. Carers talked frequently about the emotional impact on them. Words used to describe their emotions included devastated; mithered/ worried/ tense; down/ low; fraught/ short-tempered; stressed; guilty; upset/ crying and embarrassed. Isolated/ lonely was a theme specific to carers. Both people with dementia and carers talked about the emotions of people with dementia and their mental health. Many of the emotions were similar to those mentioned by carers; mithered/ anxious/ worried/ frightened/ panic; depressed/ fed up/ wishing to die; cranky/ ratty/ arguing; stressed; blaming self; upset/ crying and embarrassed. Emotions specific to people with dementia included feeling ashamed, frustrated and hopeless.

With respect to the 'physical health' theme, it was almost exclusively carers who talked about carers' physical health. Problems mentioned covered a wide range; musculo-skeletal problems were most common but weight loss; diabetes; high cholesterol; high blood pressure; chest conditions (asthma, bronchiectasis and infections); heart conditions; loss of balance and falls; hearing difficulty and needing an operation were also commented on. In contrast, the issue of physical health problems of people with dementia was raised by all groups. Some people with dementia had pre-existing illnesses affecting how they coped with the dementia, musculoskeletal conditions were most common, others had pre-existing long-term illnesses, including epilepsy, Parkinson's disease, heart conditions and diabetes. Carers commented on illnesses which had developed during the course of their relative's dementia,

and often made them overtly unwell and much more confused, including various infections, constipation, mini-strokes, collapses, falls or blackouts and seizures related to the dementia. Impaired eyesight was a problem for several people.

In relation to 'identity', carers stressed the changes in the person with dementia. Only three people with dementia addressed identity in their narratives: all stressed the continuity of self.

### ***Outcome themes***

We suggest that the outcomes of the supports and stresses acting on the experience of dementia can be understood in terms of two further themes, 'approaches to coping' and 'looking to the future'.

'Approaches to coping' captures beliefs about how to approach living with dementia. Four main subthemes are listed in Table 2. One approach is that of 'doing normal things/ keeping active', which links with the belief that keeping the brain active maintains function or facilitates routes round damage. Other people talked about 'accepting the way you/ they are'. The approach of 'just do it' was often described by both carers and people with dementia as though they had no choice. 'Keeping to a routine' was the fourth approach, which involved having a regime, a routine, a pattern or being methodical, and was linked with the problems of things happening which disrupted the person's usual routine.

'Looking to the future' was particularly difficult for people with dementia, who talked about panic when looking to the future related to the uncertainty they faced, but also the need for acceptance and planning for the future, eg making their funeral preparations, making wills and filling in papers for power of attorney, organising finances. Three people with dementia alluded to euthanasia: one to say that she wouldn't do it and two to comment along the lines that it would not bother them to die.

### ***Model***

Figure 1 suggests a model of understanding the themes identified: the symptoms/ experience of dementia are shown resting on four supportive paradigms. The exacerbating themes (or additional stresses) also influence the symptoms/ experience of dementia and shape how the person with dementia, carer or couple develops their approach to coping and looks to the future.

### ***Analysis of feedback on the process***

Feedback was received from participants in the following ways: by post (on the experiences of 6 individuals); in conversation over the telephone (5 individuals); face to face conversation at a café (9 individuals); by email (2 individuals). Four main themes were identified: 'emotions', 'putting things into perspective', 'sharing or not sharing the narrative' and 'actions resulting from producing the narrative'.

Producing a narrative had often been an emotional process for participants (both people living with dementia and carers) and they described positive, negative and mixed emotional responses. One carer described producing the narrative in very positive terms:

*“I was more than satisfied with what I did. Never been one to let anything upset me when I talk about it. I was over the moon with it – I didn’t think I could be so helpful – I was proud of that”*

but another carer had found it more negative:

*“I found it upsetting to remember”.*

A person with dementia described the process as more mixed:

*“Talking about my experiences, my journey, revealed how my life and I had changed, at times disturbing yet positive.”*

“Putting things into perspective” was a theme described by most of the carers, eg:

*“There was also a satisfaction in sorting out a chronological order to what was, as the time, a chaotic and exhausting experience.”*

Telling the story of itself could be valuable, as one carer commented:

*“you got me thinking in a different way because I’d said it”.*

And sometimes it led people to see things differently:

*“I never realised I did so much and coped so well.” (carer)*

and

*“When you say it out loud it makes it more real. It’s almost as though talking had released some of the tension.” (carer)*

One aspect of this mentioned by a number of carers, was to be surprised by aspects of the journey once the narrative was returned to them, and to only realise what they went through on taking the opportunity to look back through the journey.

The issue of 'sharing or not sharing the narrative' was dealt with in two main ways. Some people chose to share the written narrative with selected people, usually close family members, eg:

*"My daughter read it and was quite surprised at what had gone on."* (carer)

Others referred to sharing parts of the story with other people such as close friends and neighbours. One carer was planning to share the narrative with the vicar. The second way of dealing with the narrative was to treasure it: one carer said

*"I thought it was great – something to treasure."*

'Actions resulting from producing the narrative' divided into two groups of actions. Personal actions were described mostly by carers eg one woman caring for her mother with a dementia said:

*"I have told my mum that even though we all have good and bad days I still love her."*

And one husband commented about his wife who has dementia and who had produced the narrative jointly with him in a couple interview:

*"Got closer to (wife's name) since she did it".*

People with dementia talked more about public actions that they had taken as a consequence of producing their narratives and talking about their journey.

This is illustrated in the following quotations:

*“I gave a presentation last week at the (place) to over 100 people”.*

*“As a result of talking about my journey I agreed to give an interview to a local journalist ... This was a big thing for me because I had always kept “my condition” secret.”*

Some carers had also taken public steps, eg:

*“I never thought I would speak on Radio ... of some of my feelings and have wrote a description of the treatment my husband received at the hospital (which is not good) to the (local organisation)”*

and other individuals, both carers and people with dementia, had stepped forward to take part in local groups or for a connected with dementia and/or caring.

## **Discussion**

Several limitations and challenges were involved in this project. Recruitment was one. Although recruitment to the study was easier than anticipated, due to community links, and recruitment of carers proceeded relatively rapidly, identifying participant people with dementia was a slower process. The team encountered reluctance from some carers/ family members who did not want their relatives to take part in case it should upset them. A desire to protect participants from distress in talking about their illness has been observed

before, despite the fact that people with dementia are often more aware of their situation than carers recognise (Clare, 2003). Some of the people with dementia who took part found it difficult to talk about their illness journey because of their memory problems and, despite the fact that we told their family members that factual accuracy was not critical, some carers clearly felt that they should correct what they regarded as inaccuracies in dates etc: the link between narratives and memory is well recognised (Skultans, 1998). Participants came from a wider geographical area (West Midlands and North West) than anticipated as information about the project disseminated through the partner organisations. Although three participant people with dementia were from African-Caribbean backgrounds, we failed to recruit any participants of Asian origin despite making contact with an Asian community worker.

One of the challenges in the design of the project was transcribing. The spoken narratives varied greatly in length. The conversations, which elicited the narratives, lasted from less than an hour to about two hours. Transcription into a written record was onerous, and took longer than anticipated: one hour of audiotape took between four and six hours and some of the transcripts were nearly 30 sides of A4 paper in length. Our study design allowed an individual to choose how their narrative was recorded, and participants opted predominantly to audiotape their narrative: method of production might influence the narrative itself. Two narratives were submitted as written accounts: these were much briefer, having missed out on the opportunity for elaboration and development in conversation.

One factor accounting for some of the differences in the topics addressed by carers and people with dementia is that the people with dementia were, in general, at an early stage of their illness, whereas some of the carers were looking after relatives with advanced illnesses. We did not carry out cognitive testing, which might be regarded as a weakness of the study, and we did not seek diagnostic information, instead accepting the diagnoses given by participants: we aimed to concentrate on the narrative conversation and not exclude people on the basis of scores. A related factor has been described by Steeman and colleagues, who noted that in seeking to understand narratives it is necessary to acknowledge them as an expression of an attempt to 'counterbalance devaluation' (Steeman, Godderis, Grypdonck, De Bal, & Dierckx de Casterle, 2007): this may have influenced how some people with dementia and carers described their experiences and some of the difference between the two groups.

### **Findings from the analysis of users and carers narratives**

Analysis of the narratives has produced rich information about how services could better serve the families that use them. Participants made practical suggestions from which services and service personnel could learn. One example is that service providers could review how they support people through the process of getting the diagnosis and make sure that they have a contact person who will support them on their journey. Another learning point is that people with dementia and carers need an ongoing contact from

diagnosis onwards – dementia doesn't go away – and the need for continuity of care appears not to have been met amongst the participants in this project. Participants' need to enjoy life is also something that services could recognise and support. Some people will need help to find new things they can enjoy because their life has changed; others need help to carry on doing things that are important to them.

Narratives offer one way of taking learning into services to influence service design and provision, and, as 'patient journeys', have been used in practice to assist in service improvement (Doherty, Benbow, Craig, & Smith, 2009). Other authors have reported the use of interviews as a way of ensuring that people with dementia have a voice and are listened to (Beattie, Daker-White, Gilliard, & Means, 2004; Graneheim & Jansson, 2006). It is important that services consider ways to hear the voice of people with dementia as a means of combatting the competing pressures under which modern health and social care organisations currently operate. For example, from the Francis Report it would be reasonable to conclude that some of the problems in providing good quality care were related to the target driven culture in the hospital concerned and the way that services were dominated by management preoccupation with financial pressures: this could be counterbalanced by efforts to hear and attend to the experiences of service users. It is unlikely that the privileging of financial (organisational) interests at the expense of the interests of service users was unique to the hospital investigated in the Inquiry (Francis, 2013) and ways of responding to the experiences of people with dementia and

carers need to be addressed and incorporated into routine practice across the whole of health and social care.

Surr argues that the generation of stories together with relationships with others are important in the maintenance of self (Surr, 2006), and Mitty asserts that story-telling can provide information which allows connection to be made with people who have advanced dementia and are approaching the end of life (Mitty, 2010). For services and the staff working in them the content of people's narratives gives valuable information about how services operate, about how they are experienced by service users, and how they might be improved. The process of producing narratives offers a model for learning from service users and of helping people to make sense of their journey with dementia. Narratives are therefore a source of knowledge in terms of both content and process, offering a mechanism by which services could gain knowledge and improve their support of service users.

### **Findings from the analysis of the narrative process**

Analysis of the feedback from participants reveals the benefit that people derived from the opportunity to talk through the experiences as their journey has progressed. The process of learning from people with dementia and carers is something that services could incorporate into practice, by considering ways to build in feedback loops so that they get regular routine feedback from people using their services and continually review what they are doing in the light of that feedback. In addition the narrative process may

offer insights into relationships and relationship difficulties, problem solving approaches and possible safeguarding and risk issues, with the potential for interventions in these areas (Benbow & Sharman, 2014).

### **Implications for practice**

The participants who were living with dementia in particular valued the opportunity to talk about their experiences (and found it difficult to find opportunities to do so in their current situations): indeed two people living with dementia wrote to a team member several times to update her on their activities and progress after completion of the project, suggesting that they had valued the contact and relationship. A qualitative project studied 20 men diagnosed with early Alzheimer's disease (Pearce, Clare, & Pistrang, 2002). Their interviews were analysed using interpretative phenomenological analysis and addressed the following: the man's background, past and present social roles, capabilities and interests; the man's view of what was happening and how it had affected him and his relationships or social roles; how the man attempted to deal with what he viewed as the 'problem'. The authors drew two important conclusions from their work: that services 'could' identify people's strengths and resources, and that services 'need' to offer opportunities for people with dementia to talk about their experiences and try to make sense of their illness. Similarly attention has been drawn to the sense of meaning and purpose that can be found in voluntarily taking part in research and how it may be 'highly significant in terms of therapeutic potential' (Dewing, 2002). Dewing goes further, writing:

*'It is my position that all person-centred encounters are potentially therapeutic encounters for persons with dementia and must be considered from this position.'* (Dewing, 2002) page 165

Within the field of dementia care the majority of professionals would consider the person with dementia and caregivers' perspective or narrative to be of vital importance when intervention or care is planned. It is therefore essential to facilitate a constructive dialogue that promotes a process allowing the 'patient story' to be heard but how might this be done?

Is it practical to consider producing narratives with people with dementia and/or carers as part of service provision? One method of producing narratives, which might be more practical for routine service use, might be to produce narratives as audiotapes or videotapes. One carer contacted us after the study, when her husband had died, and asked if she could have a copy of her husband's interview audiotape, in order that she could have a recording of his voice to keep. Since he had consented to share his transcribed narrative with her, we acceded to this request. Thus the narrative itself appears to be a positive memory artefact for some people. If narratives were to be elicited by staff working with a family, another area to explore would be the effect of producing the narrative on the relationship between that member of staff and the family and what influence its production has on use of the service. In addition, if narratives are produced by a person with dementia or a carer, the effect of that narrative on people with whom it is shared is another potential area of investigation. Keady and colleagues have shown how an Admiral

nurse can integrate a narrative approach into care, by constructing care from an autobiographical perspective (Keady, Ashcroft-Simpson, Halligan, & Williams, 2007), and, whilst assisting someone to produce a narrative might be time-consuming, most assessment procedures can take a not dissimilar amount of time.

Finally, in a time of austerity is it practical to consider the applications of narrative production to practice? There is evidence that adequate support for families reduces stress/ burden for families, improves quality of life, and leads to lower use of care homes and in-patient beds (Brodaty, Green, & Koschera, 2003; Spijker et al., 2008; Watts, Cheston, & Moniz-Cook, 2013). If narratives are embedded in practice as part of relationship-centred care, they will bring the potential to improve quality of care and decrease the long-term costs of caring. We would argue that, to avoid future failings in care along the lines of those detailed in the Francis Report (Francis, 2013), it is essential to understand people through a personal and relational lens.

## **Conclusions**

This study demonstrates that the opportunity to talk, reflect on, accept and come to terms with dementia is valued by carers and people with dementia. Carers may have access to carer groups and other supportive contexts but many people with dementia have little opportunity to voice their fears and concerns. There are some groups for people living with a dementia and the

value of such opportunities and ways of providing them could usefully be further explored.

Relationships with others were clearly important in supporting carers and people with dementia. A range of services was described. Given the importance of relationships, a relationship-focussed approach to care and support would seem sensible and services that maintain continuity of relationships with families using them are likely to be appreciated.

How people were given their dementia diagnosis and how they developed an explanation for the illness appeared important in that some explanations offered hope, whereas others removed it. This highlights the importance of how the diagnosis is given to families and how dementia is explained to them.

In order to be able to face the future, families living with dementia need to feel supported in the face of the stresses they have to contend with. The model here suggests ways of bolstering their support, including the following: giving explanations which leave room for hope; ensuring people have the opportunity to talk about their experiences and fears; facilitating long term relationships with health and social care staff; assisting families (both carers and people with dementia) to find new things they can enjoy and to carry on for as long as possible doing the things that are important to them.

Producing a narrative is a valuable and engaging experience for both people with dementia and carers. It allows people to talk and to make sense of their

experiences: currently services offering this opportunity are only available in limited geographical areas and are not open to all people living with dementia. Further research is needed to establish whether the opportunity to produce a narrative and reflect on their experiences could be facilitated in routine practice in the care of people and their families living with a dementia. We believe that narrative understanding of the journey undertaken by a person with dementia and their family is not an alternative to a scientific evidence based medical approach, or an optional add-on, rather it is essential to see the whole picture by understanding people through both complementary lenses.

Prepublication draft

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Prepublication draft

**Table1: Demographic profile of study participants**

Variable	People with dementia (N=20)	Family carers (N=21)
Mean age	74 years	67 years
Age range	56-89 years	29-87 years
<b>Gender</b>		
Male	60%	19%
Female	40%	81%
<b>Marital status</b>		
Married	70%	86%
Widowed	25%	14%
Don't know	5%	
Early onset dementia	20%	24%
<b>Self-reported/ carer reported diagnoses of person with dementia</b>		
Alzheimers disease	35%	52%
Dementia (unspecified)	45%	19%
Vascular dementia	0	10%
Other	20%	19%
<b>Relationship of carer to person being cared for</b>		
Spouse	Not applicable	81%
Mother/ Mother-in-law	Not applicable	14%
Non first degree relative	Not applicable	5%

Category	Theme	Subthemes	Illustrative quotations
Supports	1. Relationships	i. spousal relationships	she is the background to everything I do: it's as simple as that.. She is the m strut in my life. (PWD)
		ii. family relationships	when they need support, because a baby is ill, and they are both working, y are not the grandparents that can give the support, you can't do it, ... we ca just help. (carer)
		iii. social relationships	people that I have thought would have supported us have gone by the way and people that didn't think would support us have turned out the best. (car
	2. Services	i. General Practitioners	brilliant, extremely good, thorough, fantastic, excellent, kind, understanding
		ii. Being given the diagnosis	'there's your diagnosis, goodbye, see you'! I actually came home, believe it not, and googled it. (carer)
		iii. Memory clinic and tests	we were referred to the memory consultant and that took a long time and th we had to ... he referred him, he did the tests, then he referred him for scan you know a CT scan, he has never had a MRI scan, but a CT scan. We ha wait then for that. Then we had to wait from then to get an appointment ba for the consultant ... (carer)
		iv. Third sector services	I think they saved my life (person with dementia talking about a third sector organisation)
		v. Social services	we were sat with that phone between us, this is no word of a lie, for over tw and a half hours, handing the phone from one to the other, waiting, because

			they said I am putting you through to someone and we just sat there. (carer)
		vi. Support with finances	it was £400, and I had no ... I was kind of bewildered and realised that I just didn't know whether that was too much or too little (person with dementia buying a present).
	3. Explanations		what I was actually looking for was a way where, in fact, if these brain cells were dying, to open the channel to other brain cells. (person with dementia)
	4. Prior experience of caring		
Exacerbating factors	1. Emotions		it is like bereavement, I think it is a bereavement. For that person that was there and is no longer there any more and you get an entirely different person (carer).
	2. Physical health problems		
	3. Identity		I look at her, think she is a stranger, complete stranger (carer). I am still me. (PWD)
Outcomes	Approaches to coping	i. doing normal things/ keeping active	And that's the way I want to preserve for as long as I can, to keep his mind open and alert and to, if you like, key him into habits that are good for him... change of atmosphere, a change of place, must generate some vitality, must it? (carer)
		ii. accept the way they/ you are	I was watching his early programmes, I thought: yes you do what we all do search and you search and you search, but in the end, once you can come

			back and you can accept, you have to make a different life, you have to leave your dreams behind. (PWD)
		iii. Just do it	it has got to be done ...you just have to take it on, you don't have any choice you can't walk away can you? (carer) I just keep going, that's all I can do really, I just plod on. (PWD)
		iv. Keep to a routine	
	Looking to the future		in your own mind perhaps you think about the future, but you know it is not in looking too far (couple) I have built up a file of things that will be useful for whoever is caring for me (PWD)
Experience of dementia	Symptoms/ experience of dementia	i. memory	living with the Alzheimer's it's, it's worrying what you have forgotten or what have forgotten., What have I forgotten? Have I forgotten something important The long term memory - no problem... It is the short term, the day to day memories that you rely on to function day to day: those are the ones that trouble me the most. (PWD)
		ii. BPSD	I don't think he liked me because of one or two times when he got a bit violent frustrated I suppose it was really, he would grab me. Well, I mean, obviously you put your hands up don't you, and he used to grab my hands and sort of shake me and he was trying to say something and couldn't get the words out and sometimes he would kick me. (carer)
		iii. Speech problems	the words became distorted, in as much as the words I was speaking were

			the words I meant to be speaking. (PWD)
		iv. Other losses	I was going round and round roundabouts because I knew I was in the wrong lane, or wasn't sure what exit. And then about six months ago I came to the traffic lights at the end of the road and I had to stop and think, what does the signal mean.... (PWD)
		v. Activities of daily living	You have to tell him to swallow sometimes, you see, even water, you say 'come on swallow it' because he, like, chews it. Sounds ridiculous doesn't chewing water? But you have to say swallow and touch his throat... (care

**Table 2: Themes and subthemes identified in the qualitative analysis, listed under the paradigms suggested in the model**

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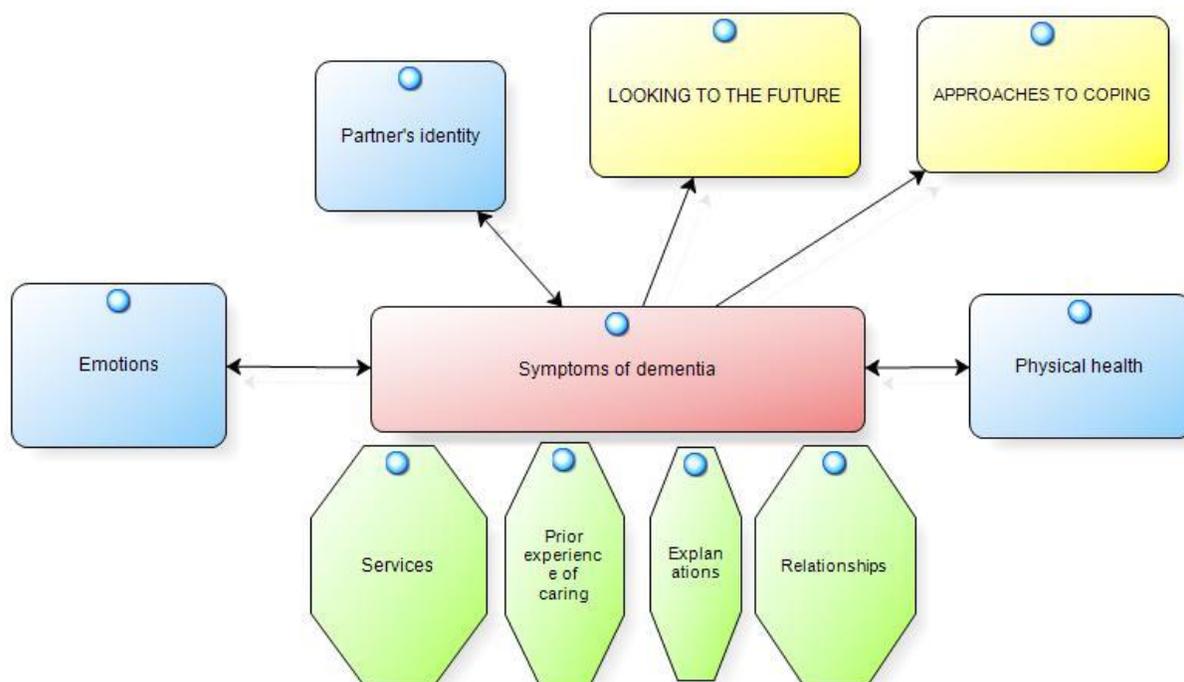


Figure 1: Model of supports for people living with dementia showing additional stresses and outcomes.

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Susan Mary Benbow trained as old age psychiatrist and family therapist and worked for a number of years in Manchester, then Wolverhampton. She is currently Visiting Professor of Mental Health and Ageing at the University of Chester, based at the Centre for Ageing Studies, and Director of Older Mind Matters Ltd.

Paul Kingston qualified as a psychiatric nurse and worked in the NHS for 27 years. He has since worked in the Higher Education Sector, founded the Centre for Ageing and Mental Health at Staffordshire University in 2006, and moved to the University of Chester in 2013 to found the Centre for Ageing Studies.

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