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### ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

#### Articulation, service use, managing and coping: understanding the needs of older people and carers living with dementia

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#### Abstract

*Background:* There is increasing recognition of the need to involve people living with dementia in research that can impact on service developments in the field. Despite this, people with dementia are still under-represented and proxy/carers views have dominated discourses of care. For nursing, understanding the views and experiences of people living with dementia is particularly important for the development of effective person-centred practices.

*Aim and objectives:* The aims of the research were to identify:

- The conditions that enable people living with dementia to participate effectively in decision-making about the use and uptake of services
- The factors that affect access, uptake and use of care services for people living with dementia and their supporters

*Methods:* A participatory and constructivist methodology guided the study; consistent with this, a mixed qualitative method approach was used to gather data. Participatory observation was used to identify key issues and key participants (four people living with dementia and four carers), who were then interviewed. The interview data were analysed using the constructivist data analysis processes of unitising and categorising.

*Findings:* Three main themes were identified from the interview data; barriers to articulation of experiences; finding help and support; and managing and coping. The impact of these issues on the choice and decision-making processes of people living with dementia and their carers emerged in a range of ways and are presented here.

*Conclusions and implications for practice:*

- Researchers and practitioners need to develop skills in engaging with conversations that may seem disjointed or to drift on to different topics
- The role of carers in interviews raises challenges, but ultimately researchers and practitioners need to balance and blend the views of carers while prioritising the voices of people living with dementia
- To be effective, services for people living with dementia and their carers, need to provide emotional and practical support

**Keywords:** Decision- and choice-making, involvement, dementia, community services, healthy ageing

## Background

As practice and research in the field of dementia have progressed, the need actively to involve people with dementia has increasingly been recognised (Menne and Whitlatch, 2007; McKeown et al., 2010; Dupuis et al., 2012; Fetherstonhaugh et al., 2013). This is seen as particularly important because previous research has tended to overlook the experiences of people living with dementia and instead focused on the views and needs of carers or other proxy voices (Hellström et al., 2007; de Witt et al., 2010; Tanner, 2012). The views of people with dementia can be seen to be even more important as studies that have worked to assess quality of life, while acknowledging the difficulties associated with this, have found that people with dementia rate their quality of life as more important than proxy carers do (Moyle et al., 2012; Sheehan et al., 2012). Studies of the experiences of people who are living with dementia have also noted that their early and ongoing involvement in decision-making processes may lead to more positive outcomes in terms of quality of life, autonomy and insights into the person's identity, and preferences (Tyrell, et al., 2006; Menne and Whitlatch, 2007; de Witt et al., 2010).

While the involvement of people with dementia is seen as positive, with research studies having identified that, even at advanced stages, they can express preferences and choices (Whitlatch and Menne, 2009), such involvement in decision- and choice-making processes has been found to be lacking (Tyrell et al., 2006; Menne and Whitlatch, 2007). The process of involvement therefore needs careful consideration, not only in terms of what people are consulted about, but also who is consulted (McKeown et al., 2010; Tanner, 2012). Indeed, where dementia or cognitive impairment has progressed, and is seen to affect issues of mental capacity, the likelihood of exclusion from decision-making is increased, particularly in health and social care contexts (Smebye et al., 2012; Taylor et al., 2012). The role of proxy views can be seen as contentious as they may not always chime with the views of the person needing care, but given that people living with dementia are most likely to be supported by family carers, research into people's needs for care and support has to be balanced by taking account of perspectives and circumstances of all those in the caring situation (Whitlatch and Menne, 2009; Sussman and Regehr, 2009; Miranda-Castillo et al., 2013; Toot et al., 2013). For nursing, the involvement of people with dementia in research and practice is particularly important for the development of person-centred care in practices and services (Digby et al., 2011). The recognition that issues of mental capacity to make decisions can preclude the involvement of the person with dementia is reflected in the UK's national dementia strategy (Department of Health, 2009, p 47):

*'Some will be in the early stages of their illness, and others near the end of their lives. The right support, at the right time and in the right place, is especially important for people with dementia, to give them choice and control over the decisions that affect them.'*

In order to understand how people with dementia and carers have experienced control and choice over decision-making processes, this paper presents findings from a participatory study that aimed to identify:

- The conditions that enable older people to participate effectively in decision-making about the use and uptake of services
- The factors that affect access, uptake and use of care services for older people and their supporters

## Methods

As people have lived experiences that are multiple and complex, this research was guided by a constructivist and participatory methodology (Lincoln and Guba, 1985; Guba and Lincoln, 1989; Lincoln, 2001). The constructivist method has gained popularity in nursing and social work research as it has been argued that an approach that enhances an inquirer's understanding of people's lives can promote more holistic person-centred understandings (Rodwell, 1998; Engebretson and Littleton, 2001; Appleton and King, 2002). Consistent with a constructivist method, a mixed qualitative approach was adopted using participant observation and interviews. Ethical approval was gained from an NHS ethics committee.

### **Study settings and participants**

The work reported in this paper was undertaken at two day services that had been developed by a dementia charity. The research was conducted at both centres over a period of six months. The first day centre was developed for people who had been diagnosed with dementia when they were aged over 65; the second centre was developed for those diagnosed before the age of 65. Both centres offer a range of activities, and the day service for younger people living with dementia had regular trips out and provided one to one outreach and support. Twelve people or their carers, out of approximately eighteen people attending the two services, gave consent to participant observation, including taking notes of activities and conversations. Following the observation phase of the study, eight people (four people living with dementia and four family carers) gave further consent to be interviewed.

The observation data were used to identify key participants and key issues to be followed up in the interviews. The interview data were initially analysed using a narrative approach to explore and identify the factors that affected individual decision- and choice-making processes (Tetley et al., 2009). The interview data were then analysed again using a constructivist data analysis processes of unitising and categorising (Lincoln and Guba, 1985; Rodwell, 1998). Unitising is described as a process in which coding a transcript, or any other document related to the research, aims to convey some form of understanding or action required (Lincoln and Guba, 1985; Rodwell, 1998). The units of analysis should be something that can be understood without further explanation; that is they are able to stand alone (Lincoln and Guba, 1985; Rodwell, 1998).

Lincoln and Guba (1985) recommend that unitising should be followed by categorising, a process in which the initial coding units are brought together to form categories. Within categorising, the two processes of 'sorting' and 'lumping' take place. Sorting brings together data units to identify relevant themes; lumping then follows so that similar units are brought together to form provisional categories. These processes then continue until clear relationships between the categories start to emerge (Lincoln and Guba, 1985; Rodwell, 1998).

### **Findings**

Following the analysis of the interviews, three issues were identified that have implications for research and practice that aim to improve understandings about the situation and experiences of people living with dementia and those who support them. These were:

- Barriers to articulation of experiences
- Finding help and support
- Managing and coping

The impact of these issues on the choice- and decision-making processes of people living with dementia emerged in a range of ways.

#### **Barriers to articulation of experiences**

On reading the interview transcripts, one of the first issues that arose was the nature of the interviews themselves. Re-reading the interview transcripts made it clear that people with cognitive/memory problems struggled to articulate their responses, or 'drifted' away from the questions asked. For example, during an interview with Lucy (one of the younger attendees at the day centre) we talked about her experience of the outreach support service and the day centre that she attended.

Lucy:

*'...it's like going back to school isn't it. I just like going to the centre, it gets me out of...'*

\*Debbie\*:

*'You just like to get... it's like when I come, and I say we'll go down... oh good we're going... you know what I mean, just anything to get out, you just love to go out.'*

Lucy:

*'[indiscernible] and try and get some cuttings.'*

Debbie:

*'Rather than sitting here, but she [indiscernible] if she saw something she'd pick things up to use to make craft with, and stuff, won't you?'*

JT (author):

*'And you enjoy gardening as well, don't you?'*

Lucy:

*'Oh I do, [...]. I do.'*

JT:

*'So as well going to the day centre...'*

Lucy:

*'And I don't like anybody... I don't have that thing that used to live next door chucking her dog ends all over my back.'*

Debbie:

*'Oh [...], nasty neighbours.'*

Lucy:

*'She used to chuck her dog ends over on my back, [indiscernible]. And she used to bang on the wall, didn't she?'*

(\*Debbie\* was a support worker from a community support service who was present. Lucy's sister was also present at the interview.)

In other instances, family members also wanted to be present during the interviews and it became clear that the presence of a carer could help, or hinder, the extent to which people were able to talk about their experiences. For example, when a man in his 60s (Patrick), was interviewed with his wife (Beryl), they talked about how he came to realise he had dementia.

JT:

*'When did you retire?'*

Beryl:

*'You were 61, 62.'*

Patrick:

*'Yes, I knew there was something wrong with me. I'd measure like that, you know, and then I'd get my saw and I didn't know where to put it. And I thought, there's something here, isn't it? But then I came back to the house and my head was like that, wasn't it? Go on, you tell her about it anyway...'*

Beryl:

*'No, you're alright.'*

Patrick:

*'Well I think for about two days, and I went upstairs about 10:00 and I thought, I've got to ask her some of this, you know what I mean, I didn't even know where I was. And so they said, right, get up there to the hospital.'*

Beryl:

*'It was after a few weeks, Patrick.'*

Patrick:

*'Was it? Aye, well...'*

Beryl:

*'And you was having heart failure. And he was working for a few week, not very well, but when you're self-employed, and men like that that's always worked, he kept on going and going and going. And then just one Sunday, that's it. I had to take him up there and he was in heart failure, and then he was going back and forth to the doctor for a few days after he'd got out of the hospital.'*

*And that's when they said dementia.'*

Patrick:

*'I didn't like that. I never took my coat off. I couldn't sleep, you know, in the hospital. And I rung up one day and... I'm going, I'm going home. Oh no... and the lad said, come on. And they came here, but oh, it was horrible that place.'*

When asked about how the dementia affected him Patrick said:

*'Well mine is talking. I can't get it out. That's top think with me. If I say it quick and [Beryl] says what? I'll have to get it in my head to think of something else. That's... I wish I was alright, but that's it, isn't it?'*

Here, as Beryl participated in the interview, her presence was supportive and encouraging. However, this was not the case in every interview and in some instances carers tended to speak for the person they were supporting. This came across very clearly in an interview with Elsie, who had memory problems. She had agreed to be interviewed in her own home but her daughter wanted to be in attendance.

JT:

*'And did you go to [name of day centre] just one day a week, Elsie?'*

Daughter:

*'No, two. You went two days a week there. She went there because when she went after initially going to the doctor's and him realising that there was... she went for something else but we'd been telling him for a year or two that we don't think things are quite right. Oh we all forget – you know, that attitude. And then he asked her something and realised when he'd asked her this question that there was something the matter. So he referred her to [name of hospital] and she was assessed there, and then they obviously had her at [name of day centre], she used to go there one day a week I think it was for continuing assessment over I think it was just something like three or four months. Or maybe it was as long as six months, I don't know. And from there she said she could only stay there a certain length of time, which she loved it at [name of NHS day centre]. And then they sent her to [name of a different day centre] and said she could go there a couple of days a week.'*

The daughter continued to talk for several more minutes explaining how her mother did not like the first day care centre that she was referred to and eventually refused to attend. She then went on to explain how this refusal eventually led them to look for alternative support. The daughter concluded her response by saying that her mother was now happy at the day centre where I had met her, but wished that she could attend more frequently [the centre was only open one day a week because of funding].

At the end of the daughter's long response to my question, Elsie finally spoke and asked me:

*'Is there anybody goes there more than us?'*

While her daughter tended to give initial and longer responses during the interview, there were points where Elsie gave a clear view on her experiences. While undertaking the participant observation at the dementia day centre, I was able to see that she enjoyed the company of others and the activities. So when I asked Elsie what she enjoyed, I was not surprised when she replied:

*'Well they're always nice and kind, and you all feel in the same boat as them.'*

These examples raise two key learning points for researchers working with people with dementia. The first issue is the risk of overlooking or missing the perspective of the person who is living with dementia, as their responses may initially appear to be disjointed or unfocused. The second issue is about whose voices are really being heard in the account and experiences of using services; in this



case, Elsie's experiences were overshadowed by her daughter's input. Recognising these challenges ultimately meant that in analysing the experiences of using or refusing services, which was a key aim of this study, thought was given to ensure that the experience of the person with dementia captured, using other data collection methods, was foregrounded while also taking account of the wider carer perspective.

Having considered how the different voices and perspectives could be accounted for in the research, further analysis of the data highlighted that finding help and then deciding to use services were particularly important. The first, and most problematic, of these was where to find help and support.

### **Finding help and support**

Having realised they needed some form of help and support, both the people living with dementia and the carers who were interviewed reported struggling to find suitable services. People living with dementia found it difficult to rationalise how they had come to realise that they needed help and it was often only at a point of crisis that people finally found help and support from services. For example, Lucy was initially sectioned. With her sister (Kathleen) and carer (Debbie) present at the interview, the three of them explained what happened.

Lucy:

*'I went in hospital for what time?'*

Kathleen:

*'When they put you in... sectioned you [name of unit removed] and then transferred you [name of unit removed], and we got you on section there.'*

Lucy:

*'Is that one of them wards where I was waving to you?'*

Kathleen:

*'Yes, when you went in the garden, went out of the wrong window... And Lucy's looking round as if to say, how have I got in here?'*

Lucy:

*'It was a little square, and I couldn't get back out of it.'*

Kathleen:

*'Four nurses had to come and grab her. When I was in [indiscernible] room she came and sat on my knee [indiscernible]. Oh my god. But they used to knock her out and I felt so sorry for her. She'd be awake for an hour a day and that was so her family could see her, and that was wrong.'*

JT:

*'They were sedating her, yes. And how did you find out about Debbie [carer]... well through [name of organisation removed]?'*

Kathleen:

*'It was all through the CPN [community psychiatric nurse] nurses.'*

Terry, who lived alone, described how he was finding it increasingly difficult to manage his daily care needs. When Terry and his daughter realised he was not able to manage his meals, they initially found someone they knew at a local café to provide meals for him.

Terry:

*'I had somebody at home doing it.'*

JT:

*'Yes, we were talking last week, [Terry's daughter] had been paying a lady hadn't she, who lived locally?'*

Terry:

*'Yes, and that used to be [the] Tea Caddy [name of café] then.'*

JT:

*'And she'd been and she used to do your...'*

Terry:

*'As soon as she pulled out of the Tea Caddy everything had gone like ... Oh no, [name of care agency] came in, and she pulled out then.'*

In other instances, too, it was family carers who initiated the process of finding help and support, but again, it was often a crisis that prompted them to seek help and support. For example, Jenny, the carer for her mother, who had memory and cognitive problems, explained how her difficulties caring for her mother were only resolved at a time when she was really struggling:

*'My cousin came and stayed with me for a few days whilst we were sorting all this out. And then the GP said, well we'll get the CPN onto it. But as luck would have it, when the notes went up to [name of hospital day centre], the consultant happened to read the notes. And he looked at them and he decided to come out himself. And he obviously assessed the situation very, very quickly. And realised ... he said, well we may have to admit. He said, I could admit obviously, and I said, we'll hang on for a few days and just see if we can find some help. If I just get a little bit of help... because at that time I wasn't getting any sleep or anything, it was really, really bad. And he came up with a placement at [hospital day centre] very quickly. And that was two days a week. So she was there for about 18 months.'*

It was interesting to note from Jenny's story that although help and support at a time of crisis came through a mainstream healthcare provider, after the initial problems settled down she subsequently declined a place for her mother at a social services day centre that could offer care several days a week. Instead, she chose a day centre that could only offer support one day a week. She explained why she had made this decision:

*'Well Mum went to [name of hospital] for assessment and the [name of centre] was one of the options at the end of the assessment period. Indeed [name of day centre] was one of the options. And as far as I was concerned it was the only option. I wanted something that was small and somewhere where I knew Mum would get stimulation anyway. And [name of day centre] was obviously the place where she was going to get this.'*

Barry, who cared for his wife Margaret, also explained that he was in a crisis situation because the day care centre they were initially referred to could not cope with his wife. He was determined to look after his wife at home but needed some support, and it was their CPN who eventually helped him find support at the day care service where I met him. As he explained:

*'I found out about [name of day centre] through visits that we had from the community psychiatric nurse because she was the first person following on from talking to our GP that we were put in touch with. And she came maybe once a fortnight and took Margaret out. And that led on to her eventually suggesting that if there was a place at [name of day centre], would we be interested?'*

The issue of the key informants/gatekeepers who helped people find out about services started to emerge in other interviews. For example, Reg, who cared for his wife Enid, recruited at one of the day centres, explained:

*'Our social worker is really responsible for the whole thing, and it's through her that you get the bookings for respite care. I just said to her, is there any possibility... well, she strongly recommended respite care last year.'*



In contrast, Jane, who supported her mother Edna, explained how difficult it had been to find out about services, even though she had some contact with a social worker:

*'It was only because I had to solve the matter, trying to get hold of a social worker. She's never had one come from the main [name of service] sort of thing. It was only because she'd been to [name of place], and I knew she'd had a social worker there. But nobody ever came out on a regular basis. And it was only when I was trying to sort her out another day centre that I tried to get in contact with her, and she wasn't available. They did send somebody out eventually. But no, most of the time it was me that was doing all the ringing up myself trying to find out where she could go.'*

These experiences of people who were living with dementia and their carers illustrate how difficult it was to find help in a planned and managed form. This is important, as the people who participated in this study reported that they were more likely to seek help and support at a time of crisis, when it was difficult to make informed decisions about the fit of services with their actual needs and aspirations.

### **Managing and coping**

While everyone interviewed was using some form of service, a will to retain some independence from services came across in the interviews. Some of the community services were able to provide support for activities of daily living, such as washing, dressing and preparing food, while other services checked that people were managing their medications. Terry, who was virtually blind, described how his home carer helped him manage to remain at home:

*'Well I'm alright usually because I've got a carer. I've got a carer in the morning, and he comes in the evening to feed me, which is good. He's a nice bloke, he sorts me out.'*

Although Terry was still managing to get himself washed and dressed, he admitted that he had started to struggle and might need more help in the future, but he also had great insight into his condition.

Terry:

*'At present, yes. If anybody wants to come and do more like, you know what I mean, I'd appreciate it. But there's not much to do unless they come and take me out. That's the main thing, is to get out, until I finish this cabbage...'*

JT:

*'Until you finish what, sorry?'*

Terry:

*'This cabbage, I'll be alright until I finish this cabbage.'*

JT:

*'What do you mean by that?'*

Terry:

*'Melon (head).'*

JT (author):

*'You mean until it [indiscernible]?'*

Terry:

*'You've got to keep laughing, Josie, haven't you?'*

JT:

*'Do you worry about that?'*

Terry:

*'I don't have to. Otherwise I'd be screwed up in a corner.'*

When I asked Lucy whether she thought she could manage without the support of her family and the services she replied:

*'Yes, I could, and I argue about that, I can manage. Even if they take my legs off I can still manage. I'd still jump off my backside to go and...'*

In another example, Trudie, who I had recruited via one of the centres, lived alone. Through my early contact with her I knew that she attended the day centre and a luncheon club, but she was aware of the possibility that she might need additional care or support. When asked about this she said:

*'Yes, I have thought of that. What would be my next step then? Well you're a carer, you know about people. As long as I can cope at the moment... I mean you wouldn't know, really and truly I feel that I could cope anyway.'*

Being able to cope was also important for carers, but here there was also a fear of not being able to cope in future. This was particularly evident in the interviews with two family carers, Jenny who lived with her mother and Barry who lived with his wife. Barry's wife had a rare form of dementia that caused memory problems and auditory and visual hallucinations. Barry always seemed very composed when he was dropping off and collecting his wife. He agreed to be interviewed while his wife was out at day centre.

JT:

*'Well, when I've seen you with Mary I'm always so impressed with your... you seem to know what you want and you seem to...'*

Barry:

*'Yes. There are thoughts go through you your mind, because I think, well, one day I might not be able to cope. I'm quite fit as it happens. I might not be able to cope, and I dread that day.'*

While reflecting on his role supporting Mary, Barry went on to say:

*'I just look upon it as a commitment, and I just want to do what's best for her. And not that every day is rosy, far from it.'*

As we talked it emerged that despite his commitment to Mary, it was this fear of not coping that prevented him from taking up the offer of a support service for carers, as he explained:

*'Now Christine [social worker] has been to visit me and every so often she sends me a letter to say there's a place for me on the next course. And I've explained to Christine at the outset that I didn't want to go. She says a lot of people say that, but they're happy when they've tried it. She said it doesn't work for everybody, but it's an opportunity to talk to people in similar situations. And I said, well I don't want to because I don't want to see round the corner. I don't want to go and talk to someone who is caring for someone who is in a far worse state than what Mary is, and fill me in with details of what life's likely to be next year or the year after. I don't want to know. I'll face it when it comes, but I don't want anybody telling me about it. I don't read articles about Alzheimer's. I don't read bits in newspapers, there's bits in newsletters I get from Alzheimer's Society. I don't read it, because I don't want to know what's round the corner.'*

Barry's explanation illustrated the use of coping by avoidance, which Folkman and Lazarus (1988) argue is one of the most common ways in which people deal with stressful situations.

## Discussion

At the start of this paper, the broad aims of the study were stated as being to identify:

- The conditions that enable people living with dementia to participate effectively in decision-making about the use and uptake of services
- The factors that affect access, uptake and use of care services for people living with dementia and their supporters

In terms of participation in decision-making, while people living with dementia sometimes struggled to articulate their view and experiences, their responses in the interviews demonstrated that they were able to express preferences and share insights related to their experiences of living with the condition. For researchers, this means that analysis and interpretation of interview data has to move beyond the words that are said, and take account of the ways in which these experiences can be given a voice (Hubbard et al., 2003). For practice, this means that nurses and other care workers need to recognise that while conversations with people living with dementia can seem unfocused and may drift away from the initial topic of conversation, this does not mean people are not able to express preferences or make decisions about the care and support they receive. Indeed, other studies of people's experiences of care and involvement in decision-making processes have similarly found that people living with dementia can express preferences and reflect on their experiences, but that a failure to acknowledge this ability can reduce autonomy for individuals and lead to patronising care interventions (Horton-Deutsch et al., 2007; Digby et al., 2011; Denning et al., 2012). However, in situations where speech appears limited or absent, alternative and creative ways of working, including the use of music and poetry, can give people living with dementia an opportunity to express themselves (Killick and Allen, 2001; Social Care Institute for Excellence, 2013). The use of creative arts work in dementia therefore has implications for education and training in health and social care. Traditional programmes of education must acknowledge the role that the arts can play and work to develop practitioners' knowledge and skills so they can use these in practice.

There were situations in which the carer's voice seemed to dominate and caution needs to be exercised over the use of proxy views, although this need not necessarily be seen as negative. Hellström et al. (2007) reflected on their own experiences of interviewing people living with dementia and their carers together, and noted that despite the challenges of joint interviewing, it could benefit both parties; it gives carers the opportunity to talk about their experiences with someone who is not involved in their situation, and the person with dementia has an opportunity to validate their feelings. In the case of Elsie, her daughter wanted what was best for her mother and wanted to reflect the struggle she had encountered to find a service where Elsie was happy. For practice and research, this means that a blended view of experiences needs to be taken, because in interviews, carers' views may be dominant and less positive about the quality of life of the person with dementia (Denning et al., 2012; Moyle et al., 2012; Sheehan et al., 2012). This highlighted to me the importance of the participatory observation that I had undertaken before the interview; through this, I had been able to talk to Elsie on her own and see how she engaged with the activities and other people at the day centre.

In terms of the factors that affected access to care services and their uptake and use, the role of gatekeepers as barriers to services is a recognised phenomenon, and the reactive nature of service design means gatekeepers are more likely to respond to crisis than to support people proactively (Stockwell-Smith et al., 2010). This may well explain why Jane, looking for day care but not in crisis, found her mother's social worker did not respond to her requests for help. Studies and reports of community and family care support these experiences and recognise that services are most likely to 'kick in' when a crisis occurs in a caring situation (Hales 2007; Toot et al., 2013). Moreover, Toot et al. (2013) found that poor and inadequate community services were a major contributory factor to such a crisis occurring. Both carers and people living with dementia also reported not knowing where to go to find help and support. This is not unique to the UK; for example, a study of family carers supporting people living with dementia in Canada similarly found that support services such as respite care were

under-used because people were not aware they, existed (Ward-Griffin et al., 2012). A European study of family caregiving situations and service use also found that even in countries with well developed 'formal' services, few family carers actually receive them. The study argued this is because services are limited and not necessarily focused on the priorities of carers (Alwyn et al., 2010; Di Rosa et al., 2011). Di Rosa et al., (2011) also found that carers particularly wanted support services that prioritised dignity and quality of life but did not find services that met these wishes. This finding resonates with Jenny's decision to decline a service that could provide support several days a week in favour of one that only opened once a week because she felt the latter would provide a higher quality and more personal service for her mother.

The capacity to manage and cope both practically and emotionally was also found to impact on the ability of people with dementia to remain in their own homes and on carer's ability to maintain their role. Trudie, Terry, Lucy and Elsie were all still living alone in their own homes. While they all received various forms of support, the feeling that they could cope and manage was important for them to keep going and not give in, even though they recognised they may eventually need extra support and help. Understanding the perspectives of people who are living alone with dementia is important, as other studies have noted:

*'The experience of dementia puts additional strains on ageing individuals, which is compounded by the practical and emotional experience of living alone' (Frazer et al., 2012, p 691).*

Recognising that coping and managing is an emotional response, not just a problem focused one, can also be seen in the situation of Barry. While he appeared to be coping by avoidance, which can be a maladaptive form of coping since the person is not taking steps to deal with the problems they are encountering, it is also acknowledged that in such a situation, where nothing can be done, avoidance or distancing allows people to cope and function in other roles, which in Barry's case was that of a carer (Folkman and Lazarus, 1988). However, Barry's interview demonstrated a balance to this as he also explained that he was committed to caring for his wife as part of his marital commitment. This reflects the findings of other studies that married carers are more likely to continue caring regardless of the support available or any difficulties that they may experience (Perry and O'Connor, 2002; Davies, 2011). Health and social care professionals therefore need to understand that to support people living with dementia and their carers requires service developments that go beyond the practical and everyday task-based services.

### **Conclusions and implications for practice**

This paper has demonstrated that people living with dementia can articulate their views and experiences of living with dementia and the services that they use to support them living at home. However, to access these views researchers and practitioners need to develop skills in listening to conversations that may seem disjointed or that drift on to different issues. While some people were interviewed alone, others were interviewed in the presence of carers. This raised both positive and negative challenges in terms of the insights gained; carers can give confidence and encouragement to the person with dementia who is trying to tell their story, but a proxy/carers view can also overshadow the experiences of the individual. Moving forward, researchers and practitioners need to recognise that there is the need to prioritise the voices of people living with dementia, while balancing them with the views of carers. In taking such an approach, this paper has highlighted the ways in which people living with dementia and their carers have struggled to find help and support that meets their needs and aspirations for care. However, alongside the need for practical help and support, the ability to cope emotionally was equally important. The experiences shared by people living with dementia and their carers revealed that managing and coping requires both emotional and practical support that takes account of the person-carer perspectives of living with dementia. This again has important implications for practice, and the development of care services.

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**A commentary by Cheryle Moss follows on the next page.**

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### COMMENTARY

#### **Articulation, service use, managing and coping: understanding the needs of older people and carers living with dementia**

**Cheryle Moss**

I have an interest in care of vulnerable people and ways of researching that help us as health professionals and as a community to understand what is needed in care, service development and implementation. Qualitative methods such as those used in this study are of interest to me because of their compatibility with practice development processes and intent.

More research is required into the needs of people and carers living with dementia. The research project reported in this paper advances our knowledge procedurally and substantively. A participatory and constructivist approach involving participant observation and interviews was used with some success to establish the voices of older people and their carers living with dementia. The three themes explicated from the data were identified as barriers to the articulation of experiences, finding help and support, and managing and coping.

Procedurally, there are lessons for researchers and practice developers. These evolve from the constructivist position of learning from watching and listening. Using observation in context, to inform further recruitment for the interviews and for the interviews themselves (focus and process) was useful; so too were the data analysis processes of unitising and categorising, and the linking of categories. The paper is light on detail about how the observation worked. From the reader's perspective, it would have been good to learn further about the strengths and possibilities that emerged from this as data and as process. While eight people were recruited for the interviews, the quoted texts are attributed to more people than this; presumably some of these scenarios emerged from the participant observation. Observation and talking with people are two processes commonly used by practice development researchers and by those advancing the culture of care in their workplaces and services. The fit of these research methods with practice development intent is likely to be high, and warrants further dialogue.

Substantively, narratives and extracts from interviews with three people with dementia and their carers were used to exemplify barriers to articulation of experiences. From this set of narrative texts the researcher draws the readers' attention to challenges that people with cognitive problems can have in terms of focus and expression of their experiences. The examples used reveal processes of support that carers use to assist the person with dementia with this expression. Practice development has, at its heart, the construct of person-centredness. Finding ways to listen to, to hear and to attend to others by facilitating their voices and expression is a skill and action that, as professionals and as carers, we seek to foster. These texts provide clues around techniques of co-constructed stories as illustrated verbatim in the stories of Lucy and Debbie, and Patrick and Beryl. The texts are also revealing of the risks of carers speaking for, and instead of, people with dementia; for example in the narrative provided by the daughter in relation to Elsie. While acknowledging the times when it might be necessary for carers to construct the narrative for people with dementia, intervention or coaching in the techniques of co-constructing stories may well assist carers and health professionals to allow the person with dementia to achieve greater self-efficacy in the articulation of their experiences.

Extracts from interviews and participant observation with six people with dementia and their carers were used to illustrate the struggles that people had in finding help and in gaining the right forms of support for their situation. Within the context of the UK National Dementia Strategy (Department of Health, 2009) where 'the right support, at the right time, and in the right place... to give them [people with dementia] choice and control over the decisions that affect them' (p 47), there is a great need to gather narrative accounts of what is working and where the policy implementation struggles to be realised in practice. What is interesting about these six scenarios is that several of the carers and people with dementia had reached crisis points before gaining community support and interventions. For most of these people, finding the right support, at the right time, in the right way had been a difficult process. Practice development is concerned with inquiring into practice and identifying where policy and practice, or practice and rhetoric, sit in contradiction with each other. This research provides some clues as to how real time, or recent narratives, of consumers' and carers' actual experiences can inform services and service providers about what is working well and what is working less well. It would have been useful to know if any of the people who were interviewed had suggestions for how things might have been different, or how services may have become available to them in more timely ways. However, the accounts themselves are revealing enough to help health professionals, other health consumers and policy analysts to engage in scenario development and likely futures thinking and strategy building exercises.

To illustrate the theme of managing and coping, examples of people living with dementia (Terry, Lucy and Trudie), and examples from carers (Jenny and Barry) were used. In each of these, useful physical, cognitive and social strategies that people use to help themselves manage and cope were identified. All the people interviewed were using services as clients or as carers. Much of practice development work relies on interventions and developments fitting the context and values of people and services. For this to happen, understanding the goals of the individuals in relation to their needs and values is central to the provision of person-centred care. In these scenarios, both carers and people with dementia realised what they could achieve in the present and carried some awareness and concerns for the future. These illustrations evoke interests in how our care and service provision can become more person-centric and future-focused, while addressing current state needs.

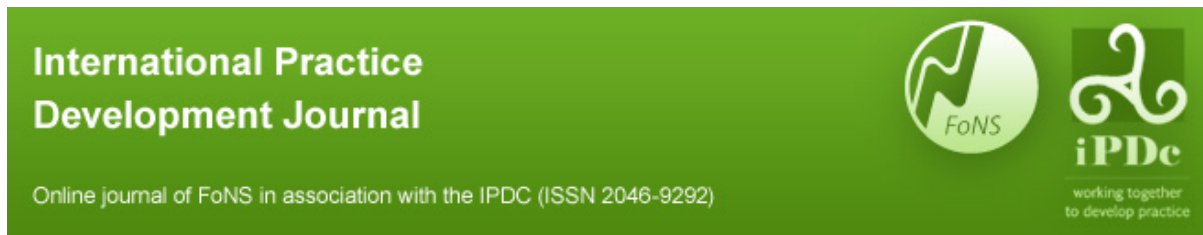
Substantively then, this research stimulates awareness of three inter-related and consequential domains of concern to people with dementia and to their carers. Finding help and support and being able to manage and cope are directly related to people's values and needs and the match of services and care to these. Timely interventions, and appropriate person-centred care, as sought by practice developers, can be achieved. Yet, as this paper reminds us, the voices of carers and people with dementia are needed to assist us with real-world understandings and examples from which to challenge and develop practice and policy. Without attention to the first finding from this study, that people with dementia may struggle to articulate their experiences and needs, it will be difficult to achieve this. The lessons from listening, and the practice of co-creating stories, may help in this quest for articulation and understanding. The findings and the research processes have merit and give rise to focused strategies that build genuine person-centredness, fit between policy and practice, and awareness of people with dementia or their carers' present and future states of hope and resilience.

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**A response to this commentary by the author follows on the next page.**



## RESPONSE TO COMMENTARY

### **Articulation, service use, managing and coping: understanding the needs of older people and carers living with dementia**

**Josephine Tetley**

This reflective commentary raises some important issues from my paper for practice development and research. As a nurse, and as a researcher, I have learned that skills in observing and listening are essential if I am to understand the needs of people I am supporting or working with. However, it was only when I was analysing the interviews reported in this paper that I really started to understand how and why the views of people living with dementia might more easily be over looked or lost. The fragmented conversations made the analysis of the interview data difficult. Indeed, when I first started the analysis I 'over-analysed' the data, breaking it down into so many codes that the data stopped making sense. I had to stop and restart the analysis process, taking account of the nature of the interview data that I was working with. This was important for my development as a nurse and a researcher, as working with this data helped me to understand how my thinking and analysis of data and situations has to move beyond applying and using the procedures I have been trained to use.

Once I had re-analysed the data, taking account of the initial challenges, I was able more effectively to draw out the challenges and experiences encountered by the people I had met. As the commentary highlights, the three emergent themes are inter-related, but so are the worlds of people living with dementia and the people who support them. By drawing on the data in the way I did, I felt I was able to show how people's circumstances and caring relationships are intertwined and inter-related, which adds to the depth of our understanding of people's experiences. The emergent themes and issues identified should then help those involved in the planning and delivery of health and social care services think about more effective ways to work with people with dementia and help them find support to remain in their own homes for longer.

I am grateful to the commentator; the commentary gave me feedback that enabled me to reflect more critically on what I had encountered and what I was trying to achieve, in ways that moved beyond some of the more obvious objectives that had been the original motivators for this work.