



P·R·O·P 2

Practitioner Research : Outcomes & Partnership



centre for research on
families and relationships

***Resilience and wellbeing in people living with
dementia in relation to perceived attitudes in their
communities***

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Introduction

Pressures on service provision for people with dementia are increasing. There is a growing focus not only on service delivery, but also on what services should look like from the point of view of the person being supported (Wilkinson and Weaks 2008). A considerable amount of care and support is provided informally by unpaid carers and community resources (Alzheimer Scotland 2010). There is increasing recognition of the need to nurture and use these natural supports which include: the assets that people with dementia and carers bring and the support provided within communities (Alzheimer Scotland 2010).

It has been long established that people with dementia are at risk of becoming socially isolated and disconnected from their local communities (Scotland's National Dementia Strategy 2013-2016, Snyder 2001). Following consultation with over 24 people with dementia and others, it was reported that perceived attitudes contributed more than environmental factors, to a community being considered dementia friendly (Milton 2012). Reactions from others on learning of an individual's dementia diagnosis can have a significant impact on the person with dementia's sense of self (Langdon et al 2007).

This study sought to explore the perceptions of people with dementia in relation to attitudes within their communities and how they respond to these perceived attitudes and behaviours. To understand how this impacts on their resilience and sense of wellbeing by asking these questions;

- What are the perceptions of people affected by dementia regarding attitudes in their communities?

- How are these perceptions formed?
- How do people affected by dementia respond to these perceived attitudes and behaviours?

The attitudes people with dementia perceive can influence how they feel about themselves as a person (Langdon et al 2007, Macrae 2011). These studies examined how reactions from others might impact on the lives of people living with dementia. Although both studies identified that people with dementia share their diagnosis with family and loved ones, they are reluctant for several reasons, to tell people in their wider social circles. Macrae (2011) expressed surprise at the lack of negative comments from her study participants regarding other people in contrast to other researchers' findings such as Langdon (2007). Macrae (2011) goes on to speculate this may in part be due to the strong support systems all the participants had both at home and in their communities.

It has been suggested that people's prior knowledge and expectations potentially amplify the stigma of dementia (Jenull et al 2012) and that the views they held about dementia before they were diagnosed might affect how they feel about their condition and consequently how they expect others will behave towards them (Judge et al 2010).

This study focused on how people with dementia feel about the attitudes and behaviours they perceive amongst their communities. Three men, Peter, David and Alex, participated in the study, in each case their wife also took part in the interview. Names have been changed.

Findings will contribute to a growing evidence base around dementia friendly communities and how they can be best developed. In particular, the study identifies the valuable contribution of natural support alongside traditional, in improving quality of life and wellbeing for people with dementia. This will be of interest to health & social care service providers and key community stakeholders.

Methods

Approach

The researcher required an approach that allowed her to get to know the person with dementia. Ethnography is an unstructured approach that allows the researcher full access to people's lives by becoming fully immersed their community, however, that was not possible for this small-scale study (Punch, 2005). Instead a phenomenological approach was used as this enables the researcher to focus on the experiences of the person, discover how they perceive an event and how they interpret their experience (Flood 2010). It is particularly useful for smaller studies of up to 10 people where there is the time and possibility for mining deeply alongside an individual (Connelly 2010). Open questions are encouraged as this leads to discussion with discovery of stories and experiences. Other researchers have recommended phenomenology as an approach suitable for people with dementia (Fetherstonhaugh et al 2013). It holistically embraces the uniqueness of an individual's lived experience (Connelly 2010).

Participants

Given the subjective nature of the research questions, it was felt that only people with dementia were uniquely able to answer them. This approach is supported by several in the field (Cubit 2010, McKeown et al 2010). It is becoming the norm to include people with dementia in research, valuing their opinions, capturing their personal essence of living with the condition thereby making a purposeful contribution to services that affect them (Murphy et al 2014, Wilkinson 2002, Wilkinson and Weaks 2008).

Approach to interviewing

The research questions were complex and if posed directly, potentially stressful even impossible for the participant to answer, especially if there were communication difficulties. Talking Mats was selected to support semi-structured interviews. Talking Mats is a low-tech communication tool using pictures, which aims to help people with dementia, and others to express views, feelings and opinions (Murphy et al 2010). Research has shown that using Talking Mats helps people with dementia to organise their thoughts and reduces distraction (Murphy and Oliver 2013). The researcher felt this would be useful regarding keeping to topic during semi-structured interviews. There are two Talking Mat versions: physical and digital, this study used the former. The participant was asked, "How do you feel about...?" as they were handed a matching picture card. This was repeated until all cards are placed on the mat. On completion, reflections were given regarding the finished mat and the participant had the opportunity to make alterations. Audio recordings captured the rich dialogue and

completed mats were photographed and retained. As a practitioner using Talking Mats in practice, the simple repetitive style of questioning shifts the focus away from the interviewer and towards the person with dementia, who remains in control, holding the picture card in their own hands, placing it where they choose. Talking Mats was chosen as there was evidence of it being of benefit to those living with dementia (Murphy et al 2010)

Some consideration was given to forming a focus group prior to the individual semi-structured interviews but the subject matter was felt too challenging for an open group. In addition, while the researcher was skilled in facilitating groups for peer support, there was an awareness of the different skills required in facilitating such a group for research purposes.

An interview guide was developed (Appendix 6). This simple guide included repetitive open questions based on feelings. In practice it might be better described as a map, navigating the researcher amongst the picture cards in different packs, directing her to cards relevant to the ensuing discussion of topics. For example, a card might read, "How do you feel about going to the supermarket?" Card selection at the outset was led by getting to know the participant, then moving onto research related topics such as: communities, going out and coping. There was an openness to this process encouraging the participant to talk freely. The purpose was to build rapport, and also to provide opportunities for the participant to relate the pictures to their personal experience of dementia. Included in the interview guide were prompts such as, "Tell me more about that..." and reminders to seek clarification on what was being said

(May 2011, Todres in Holloway, 2005, ch7).

Interviews were held in participants' own homes. Written consent including for audio recording was received before starting the interview, (Appendix 3). Comfort was assessed throughout the interviews, ensuring participants remained comfortable and were happy to continue.

Recruitment

Participants were recruited through Alzheimer Scotland Dementia Cafés following the organisation's ethical approval (Appendix 4). Inclusion criteria being: not previously known by the researcher, a diagnosis of dementia of at least 6 months plus a willingness and ability to discuss dementia. Carers were also invited to participate alongside the person they cared for. The researcher attended the cafes to meet people with dementia and discuss the research. Generic information sheets were shared together with a participant leaflet. The latter was designed to be read easily with the use of simple language, short sentences and photographs (Appendix 2).

Interestingly, research was a topic introduced by other attenders at one of the cafés leading in nicely to a discussion about this study. Three people with dementia at three different café's agreed to participate, no-one declined.

Potential bias in the results was considered in recruiting people who were already engaging socially by attending a dementia café. The opinions of those disinclined to socialise could not be sought. However, this was a small scale, exploratory practitioner research project with time constraints which could not

accommodate a lengthier process to include wider recruitment. This potential bias was considered during analysis. Those interested were contacted by phone to check they still wanted to take part and if so, to arrange an appointment at home, no-one declined at this stage.

Data analysis

Following the principles of interpretive phenomenological analysis, transcribing was carried out in full. Listening to the interviews several times gave the researcher first impressions and picked up the tone of the conversations. Concurrent analysis is a process where the researcher does not wait until all the data has been gathered but begins analysis from the outset. This allows for alterations in subsequent interviews, rendering the process flexible (Gibbs 2007). Following the first interview, the researcher identified that more time than necessary had been spent building rapport, for example by using many cards not relevant to dementia. Rapport had come easily and the conversation flowed, so in the second interview the time spent building rapport was reduced to suit the natural conversation flow.

Ethical considerations

It is considered good practice to involve people with dementia in research that may have an impact on their lives or the lives of others affected by dementia (Scottish Government 2013-2016). Fundamental to this is ensuring that informed consent is obtained. Whilst this offers challenges, these are not insurmountable (McKeown et al 2010). The researcher has strong local links with the Highland branch of the Scottish Dementia Working Group. In sourcing participants the

natural choice might have been to approach these members to become involved but the researcher felt sure they would agree primarily out of loyalty and willingness to help which might bias the results. Meeting people with dementia previously unknown to her at the dementia cafés reduced those risks, enabling her to be seen purely as a researcher. It is likely that with further research experience, the researcher would become skilled at minimising potential bias in this way with people known to her. From the outset, information was provided in clear, plain English, both verbal and written, with a full explanation given on why the research was being done. Participants were reassured that they were free to withdraw at any time and the researcher remained attentive at all times to the comfort of the participant. The participants were observed at all times for signs of tiredness, frustration or distress as it is beneficial to check for agreement throughout the interview and not only at the start (Heggestad et al 2013).

Interviews were carried out at a time that was mutually suitable, individually in the participant's own home. Written agreement was sought and a consent form produced for signing if the participant was able to do so – if not, then the researcher accepted verbal agreement, audio recorded. All data obtained was anonymised and stored securely either in a lockable case in transit or lockable filing cabinet in the Inverness Dementia Resource Centre until it could be disposed of safely. The researcher had sole access to the data and any records held electronically were password secured. If second interviews were required for any reason, consent would be sought again by reviewing the agreement form, clarifying they were still happy to proceed. This research study received ethical

approval from Alzheimer Scotland the researcher's employer.

How themes emerged

The transcripts were read several times to identify emerging patterns and themes, surprises, anomalies using an inductive process (Pope et al 2000). Categorizing, organising and coding were an on-going, flexible process (Bryman 2002). Memos were used to highlight themes in each transcript to then allow comparisons with each. The analysis aimed to look beyond what was being said to explaining the meaning behind it (Bradley et al 2007).

Findings

Common themes emerging were:

1. Telling people about their diagnosis
2. Previous life experience of dementia amongst family and friends
3. Living with dementia
4. Getting on with life

1. Telling people about their diagnosis

On telling people in their communities about their diagnosis, Peter and David did not report any negative reactions. They both described not telling people unless they had to, but when they did so people seemed to understand.

They both expressed this in quite different ways:

I've never told them, no, never said. Never felt there was any real need to like you know if I am able to do, if I am able to order a paper and pay for it

and everything I didn't need to and that's it

(Peter at the newsagents)

Eh no, they ask about ye, ye know and how you're keeping and that

(David at the barbers)

Reactions from friends and neighbours:

And eh, nobody seems to laugh or anything like that you know

(Peter)

*Yeah, yeah now I'm not shy to say to anybody like you know really but I
don't go round and say it for no good, when I don't need to*

(Peter)

well it was alright

(David)

Alex said people can ask how you are but that they '*they don't dwell on it*' so he was asked if he thought people avoided the subject of dementia;

To a certain degree, which suits me

Alex went on to talk about an isolated situation, '*that was a one off thing that*' where he did not receive help despite explaining he had Alzheimer's disease. This was from a person known to Alex and his wife within the church community which only exacerbated the situation for them.

He was in our church which was worse

(Alex's wife)

Alex and his wife disagreed on whether this would affect him going out, Alex stating:

No that wouldn't stop me.

Yet his wife reminding him:

You felt very badly for days you didn't want to see 'that man'

What is interesting about this situation is that it was recounted by Alex's wife, not Alex himself. He only talked about it once prompted by her;

'oh yes aye that was the only time'

Including carers in the research process can affect what is discussed. It is worth considering whether Alex would have mentioned that incident if his wife had not been there to remind him. All of the participants' wives were present during interviews, the other participants did not recall any negative responses and their wives did not contradict. The decision to include carers was made early in the planning stages but it does raise the question of whether that inclusion is a benefit or hindrance. In the 'I' poems discussed later, David through his use of 'you' or 'we' in deference to his wife's presence did not use the 'I' very often. So for example, he would say '*you like cruising*' or '*you like going abroad*' when it is

becomes evident that she is not alone in this preference when being asked '*what about you?*' David states; '*I enjoy the holidays I must admit*'. For that reason his 'I' poem does not completely reflect David as a person as so much content is left out.

Despite the negative incident mentioned earlier, Alex's wife goes on to say;

But on the whole people are very good

She is not alone in this sentiment;

Everybody's been very good

(David's wife)

Peter talked about his willingness to talk freely about his diagnosis, more so than the others. David described a warm, friendly relationship at the barbers but as yet he hadn't told anyone there about his diagnosis, so he was asked how he thought they would respond if he told them:

och I wouldn't think it would make any difference you know eh.....they might sort of worry about you more you know, that kind of thing but em.....no I don't think it would come into it

So despite David not telling many people in his wider circle about his diagnosis, he didn't anticipate any problems. David went on to sum up how he felt about his diagnosis:

I didn't look on it as a stigma, more of an inconvenience you know

In contrast, Peter did give examples albeit half-heartedly of telling people about his dementia *'I can sort of say to people that I've got dementia'* but this was contradicted by his wife:

He doesn't tell them

Peter and his wife talked about his difficulties recognising people's faces and how that puts him off.

Yeah but eh...there will be people there that speak to you, 'oh hello, how are you doing?' and you're eh....I wish I knew your name

Not recognising people's faces, not knowing their names, Peter goes on to say it might be better to speak with people he doesn't know so he doesn't have to explain why, to reveal his diagnosis:

I think that's part of the thing you know, eh maybe with the dementia you should talk to people you don't know so you don't have to tell them

2. Previous life experience of dementia amongst family and friends

Peter was invited to talk about other experiences of dementia and he talked about his grandmother:

Oh yes my granny aye it's a long, long time ago and she, she had a bit of a problem. My grandfather used to take the mickey out of her and I didnae like that

He was encouraged to talk more about that:

Aye well, she didn't eh I mean she just got a lot of things wrong and he laughed about it you know. For neither of us that wasn't very nice

On the likelihood of that happening to him Peter replied:

I suppose maybe at this stage but ah, ach I've just got to accept it

Again he talked about attending the dementia café:

That's obviously a help aye you know and you know they're not going to laugh at ye

Did this mean he expected people to laugh at him?

Well no but in some cases they do. Some people do.

It was important to find out if he had actually experienced being laughed at and he replied:

Aye not well.....but I have the odd occasion, I can't remember who the last one was about

Peter's uncomfortable memories of his grandmother being laughed at could be the cause of his reticence in talking about his own condition with his wider social circle and fear of being laughed at himself. Not enough is known about his grandmother's situation. It is possible that his grandparents had a different sense of humour, that Peter being young, might not have understood or perhaps he was simply sensitive to his grandmother's discomfort.

David's experience of dementia was in relation to caring for his father who also had dementia. His perception of that is quite different to that of Peter's. When David was asked to talk about whether his past experience with his father affected him today with his own diagnosis he said:

No I thought it was an advantage to be quite honest...

I think I learned a lot from my father having it first you know

David describes his father's attempts to get out of the ward he was in, even climbing a wall when he couldn't get out through the locked doors;

but they (ward staff) used to have to watch him and I kind of admired him for that you know!

He talks about when the ward staff asked him how he felt about them naming a pet hare after his father, who was a fast runner. David thought it was very funny:

'You'll no be offended?' but no I saw the joke

Alex had no experience of dementia among family and friends. Here we have three people attempting to make sense of their lives with a diagnosis of dementia. David and Peter experienced dementia in close relatives prior to their own diagnosis whilst Alex did not. These past experiences could be to some extent affecting their coping skills today, including how they anticipate problems and how they are responding to people in their communities, although it is not a factor in isolation. David had what some might describe as a negative experience of dementia with his father but for many reasons including humour, David does

not view it in that way even seeing it as a learning opportunity helping him live with his own diagnosis.

3. Living with dementia

A recurring word or theme running throughout Peter's interview was '*doing something wrong*', '*stupid*', '*being laughed at*'.

Well, you don't want to look stupid really, maybe if you are a bit stupid now but you try and avoid it that's the thing

The key word here alongside stupid, is '*now*'. It is likely he means due to dementia and talks about avoiding that. Few people would want to appear stupid and Clare (2003) describes the situation where people with dementia work hard to appear more cognitively intact than they are. People with dementia are caught between a rock and a hard place. Their diagnosis can be questioned if, due to their insight and hard work, they do not exhibit the expected symptoms of dementia. The context of Peter's comments was in a discussion about the dementia café where he felt a common bond, '*in the same boat*', '*similar people*':

If you say something stupid well eh they accept it you know that kind of thing

A reflection was given for him to expand further; *Being accepted is really important...*

it is really, aye, that's it, that's it

During a discussion about telling people of his diagnosis, Peter and his wife expressed different opinions on how sociable he is:

Aye, yeah, I'm no out and about talking to a lot of people

(Peter)

Then later in the conversation:

You were a very sociable person

(Peter's wife)

Yes, always was, always got on well with people but eh now it's

(Peter)

A previously sociable man who is withdrawing from his community Peter appears to fear being laughed at or made a fool of and this could be related to his memories of his grandmother. Individual perceptions and attitudes such as these contribute to health and wellbeing alongside clinical symptoms and therefore practitioners need to consider every aspect of the person with dementia.

Alex and Peter both talk about how dementia impacts their daily lives such as doing the shopping;

I can know about something and if I turn around it'll go

(Alex)

I know I've to get 3 things but what 3 things?

(Peter)

All of the men talked about how it was good to chat, be sociable but David being of a friendly nature takes this a bit further when asked about strangers in his

community, people he does not know;

Em they don't stay strangers for long

4. Getting on with life

All of the men talked about 'getting on with it'. David took a pragmatic pro-active approach:

You've got to be positive and try to do what you can do

He considered that others may have more challenges related to his diagnosis than he does:

Aye, but no eh... the dementia I think can affect the family probably more than the person that's got it

(David)

Talking about dementia 'not getting better', Peter says with resignation:

Aye, you've just got to accept that like and there's certain things I wish, you know I wish I wasn't like that like you know but you've got to live with it, you just have to live wi it kind of thing

Peter's comments could represent an attempt to be stoical, in line with perceived cultural expectations eg maintaining a 'stiff upper lip'. It was a common theme;

Well whatever, I'll just have to still make the best of it

(Peter)

Alex talked about other life challenges and how he had been a fighter. He was asked if that was helping now;

I suppose it is yeah, I never think of it like that but yeah, yeah you've got to fight. You can't throw the towel in

David was asked to expand on the experience of seeing his father with dementia and whether that might make it harder for him to then live with his own diagnosis;

No I just get on with what I can do and what I can't

He does acknowledge that it's not always as straightforward as that:

You still try to be as enthusiastic as you can about things you know but sometimes you're not, you know you're just a wee bitty, eh well or you just don't feel like joining in you know

When he is asked about coping and if his personality makes a difference David goes on to say:

I suppose so, I'm not one for worrying about things I canna change

Discussion

The process

The researcher sought to understand the lived experience of people with dementia in relation to how they perceive attitudes in their communities and how they respond to these perceptions using a phenomenological approach. This

involved immersion in the data relating to participants' experiences, seeking to understand it from their perspectives. Within this small project this has been achieved to some degree. By getting to know these three men in depth, the researcher gained some understanding of how they are living with dementia and in particular some insight into why they hold certain perceptions.

Limitations

Phenomenology is compatible with the person-centred approach that underpins good dementia care as practiced by the researcher. There are however, limitations to its use. Phenomenology presents the new researcher, such as in this study, with many challenges. Exploring the phenomenon of living with dementia in a natural setting, using semi-structured interviews, produced a large amount of data with barely 40% being relevant to the research questions. This, in part, could be due to the naivety of the skilled practitioner as a novice researcher. However, there are examples of probing and clarifying giving the participant the opportunity to go into more detail if they chose:

You expected people to laugh at you?pause

(to Peter)

You saw it as an inconvenience?pause

(to David)

There are also examples of cues being missed during the interviews that were

picked up with transcribing. For example, there were some comments that could have been examined more deeply. Rapport was established easily and these men readily shared their experiences of living with dementia, but on occasions, in particular when Peter was talking about feeling stupid and making mistakes it would have been insensitive to probe further. Heggstad and colleagues (2012) talk about 'moral sensitivity' when involving people with dementia in research. They describe how being touched by what is shared, helps researchers empathise. Therefore, on reflection the instinct and decision not to probe further on sensitive issues was ethically sound.

The process

The researcher must consider the effects of taking part on the participant. Research should include an overall aim for the process to be therapeutic, with participants benefiting from having their views heard (McKeown et al 2010). A return visit might have been beneficial in this instance but that was not possible due to time and work pressures. The amount of learning associated with conducting qualitative research and understanding different approaches was at times overwhelming for the practitioner researcher. However carrying out this work has represented a significant learning experience. It was reassuring to read that many other practitioners new to research had shared similar experiences (Norlyk and Harder 2010).

Ethical issues encountered

All participants required repeated explanations of the Talking Mats tool particularly at the outset which did not distress either Peter or David. However

Alex did not manage well with it. Handling the cards himself did not help and the researcher had to privately acknowledge his discomfort when he said, '*you're gonna be here all day*'. The cards were put aside and referred to only as a guide to prompt discussion. The conversation flowed more naturally after that. This was the third interview so increased confidence in the process and familiarity with the tool helped the researcher adapt to the participant's feelings.

Recruitment

It was unfortunate that only three people and in particular, no women were involved. Attendance at the cafés can be sporadic and on the days the researcher attended the only new attenders were these men who fortunately all agreed to participate. Todres (2005) attempts to reassure us that with a phenomenological approach it's not the sample size that matters but the quality. With the overarching aim being the deep mining of individuals' lived experiences he suggests that even between two sources of data there will be enough shared and opposing experiences to examine. One participant can also be sufficient. Even so, the researcher felt that even with a small number interviewed, the female perspective would have added to the findings.

Potential bias

There was previous mention of how some people with dementia, for several reasons, cut themselves off socially. There was a concern that by only interviewing people who have attended a dementia café those disinclined to socialise, in particular following a diagnosis of dementia, were under-represented

and that this would bias the findings. Of the three men interviewed, only David expressed having a good social life.

I think I have a pretty good social life

Corroborated by his wife, the comment below refers to the Alzheimer Scotland Football Reminiscence Group:

I can't get him out of the social centre, can't get him out of the football the other day

(David's wife)

Dementia cafés are pop-up cafés where people can just drop in. They are advertised widely, often by dementia link workers who provide post-diagnostic support (National Dementia Strategy 2013). All three men were introduced to the cafés through their link worker, but it was clear that David and Alex were more willing than Peter to socialise in this way. They describe attending many other groups, often on a daily basis whereas the café is Peter's only social outing.

Attending the café is a pivotal new event for Peter and has the potential to alter his outlook and increase his socialising opportunities. So to some degree, his perceptions may represent those disinclined to socialise. Asked about trying new things, he described getting used to the café:

Well I'm not against going to the café like you know, it's eh, I felt a wee bit better this last wee while, more confidence like you know

'I' poems

Poetic prose in the form of 'I' poems, described as the 'voice identified', can be a beneficial way to demonstrate data in a more authentic way due to researcher interpretation being put aside (Edwards and Weller 2012). Nichols et al (2014) highlight 'I' poems as a method of bringing about a power shift between the researcher and participant.

This appealed to the researcher as way of ensuring that the voice of the person with dementia, was heard. Developed from the feminist method, Koelsch (2015) recommends their use in particular with difficult subject matters as a creative way to engage with people.

All 'I' poems produced reflect the same order as the transcripts as a way of identifying changes or flow (Edwards and Weller 2012). Stanzas were created to create emphasis on themes discussed plus other sentences but nothing was added. Only participants' words are used, but some were deleted, described as 'poetic license' by Miller et al (2015). With the growing recognition of patient stories, poetry can be seen as just another route to tell a story. These three poems simply narrate the interview conversations and how they progress from rapport building, getting to know the person through to talking about dementia. As the researcher discovered there are limitations to this method with particular reference to David's poem not reflecting the richness of his dialogue due to his use of 'you' and 'we' in reference to his wife.

Alex

*I can't write
I couldn't read a book or anything
I don't mind
I don't know*

I've got friends

I get in a tizz

*I fool about singing
I don't sing in the house...If I could sing heh heh*

*I can't do it myself
I wouldn't be safe
I don't mind a bit of shopping
I can know about something and if I turn round it'll go
I wouldn't tell a lie, I'll tell you that*

*I don't need to monitor when I'm getting better
I'm getting worse
I'm certainly not getting better that's for sure
I would be quite happy just as I am you know, rather than a deterioration
I'm not scared
I'm aware of it
I'm certainly not the person now that I was*

*I was an advanced car driver
I failed that miserably
I thought it would be easy
I drove all the time
I never really thought*

*I get desperately tired
I'm a wee bit wary
I know full well that I've got it*

I'm dancing!

*I don't go down for a newspaper
I used to
I know everything I should know
I can't put a word into it*

I was quite prepared

*I'm a very poor passenger
I feel guilty
I can't do it
I don't have the strength for it
I've accepted it*

*I get quite busy
I can't sit about doing nothing
I've got some friends you know
I'm very busy
I was just in a mega tizz but now it's just flowing away like
I've always said it in fact that eh there's people worse than me, definitely*

David

*I usually manage
I like arts & crafts aye
I'd rather watch the telly
I'm not good with the radio*

*I'll give you an answer
I can remember
I think I was getting myself suffering
I think actually that pills are starting*

*I was a bit slower
I wasn't wantin to play
I was keeping them back
I played for them
I was quite pleased
I wouldn't give it up*

*I didn't look on it as a stigma
I think I learned a lot from my father
I was seeing other ones as well
I found it pretty hard walking along the corridor
I felt like just going back*

I saw the joke

*I just get on with what I can do and what I can't
I haven't got the patience that I used to have
I think when you're dying you're dying*

*I've accepted it now you know
I'm no the first
I always think there's somebody worse than me
In fact a lot probably*

I'm not a singer

*I stopped going
I was doing other things
I like the pottering
I'm surprised how much I've enjoyed it
I am thoroughly enjoying it
I must admit*

*I mean you're talking to people and that's it
I think that's a big part of it
I think I have a pretty good social life
I do know a lot of people
I'm quite happy*

*I think there's a big improvement from my father's day you know
I'm not worried about my confidence in myself
I'm not one for worrying
I mean if it's out of your hands
I think we just get on with it*

I don't like to say too much about it

Peter

*I tried for a while
I take the cats for a walk
I help a bit
I don't mind it
I don't mind it*

*I don't see many of them nowadays
I had good friends
I still meet some of them
I phone him*

*I lost my, my memory altogether
I'll remember I'm getting three but three what?
I was getting her frustrated*

*I'm annoyed about it
I had a good memory*

*I'm alive but eh not living too good
I can get on with it
I enjoyed being abroad
I was in the army*

I'm still in control of myself

*I do the bits
If I'm good enough
If I'm allowed
I do have a try*

*I like to see the garden looking nice
I'm the labourer*

I'm driven down

*I can kinda get through most things like
I'm not just stuck completely you know*

Conclusions

This study sought to answer the following questions:

- What are the perceptions of people affected by dementia regarding attitudes in their communities?
- How are these perceptions formed?
- How do people affected by dementia respond to these perceived attitudes and behaviours?

In terms of telling people, there were disparities; all three men said they didn't mind telling people about their diagnosis but at the same time they didn't offer this information unless there was a real need, preferring to avoid it if at all possible. Alex comments that people sometimes avoid talking about dementia;

to a certain degree, which suits me

Only Alex reported negative attitudes in his community. He talked about asking for help but being declined. Although his memory of the incident was not clear, his wife recalled how upset he was at the time; *'he really felt he didn't want to go out'* which has implications for his health and wellbeing and that of others in similar situations.

Two people with dementia identified previous life experiences of dementia which may have affected how they feel about their own diagnosis. All past experiences were described as negative, but their responses were both positive and negative, *'I think I learned a lot from my father having it'* said David, indicating that other

things affect his perceptions of living with dementia today, not solely previous experience.

A frequent theme from everyone was of coming to terms with who they are now, getting on with it, resilience and resignation.

You can't throw the towel in

(Alex)

I'm learning to live with it

(Peter)

There's probably worse things, like cancer

(David)

I would be quite happy just as I am now you know, rather than a deterioration

(Alex)

Individuals perceive their situations quite differently. This might appear an obvious statement but two men described difficult past experiences of dementia, yet only Peter reflects negatively on that. Reasons for this difference are not clear, it may be due to personality difference or to each individual's particular past experiences. Past experiences and internal dialogues/pressures may have been having a more negative effect on Peter's life today compared with the others. We need to look beyond people's lives with dementia today and consider their past experiences when looking at what services and support people need. Peter is fearful of people's responses to him, including them thinking he is stupid

despite no actual negative encounters in his life today. That might be in part due to his past experiences as suggested by Jenull and colleagues (2012) and Judge and colleagues (2010)

The researcher was unable to gauge how either Peter or David felt about attitudes in their communities as neither reported any negative experiences. Although David hadn't told many people about his diagnosis he didn't anticipate anything would change if say for example he decided to tell his barber, '*I wouldn't think it would make any difference you know eh...*' he clarifies this further with, other than being more concerned about his welfare '*they might sort of worry about you more you know*'. It is likely that this comfort and security he feels in his local community is bolstering him. Macrae (2011) had suggested that a lack of negative comments from people living with dementia might be due to good support and David certainly has that, not only from his family but others around him. The situation discussed by Alex was negative but as he said, was a one off. All of the participants described people's reactions as positive on the whole. A larger study would likely capture a broader spectrum of stories. Discussions abound on the language used when talking about dementia but this was not mentioned by participants at all. With further exploration the researcher would endeavor to discuss media issues, headlines and the impact that can have on the individual.

The findings of this research do not claim to be representative of all people with dementia. However, understanding the perceptions and experiences of individuals can feed into the Dementia Friendly Communities debate and inform

the development of services and community supports. Rich dialogue from people's stories is becoming a standard route to developing ways of building services around people's needs (Doherty et al 2009, Wilcock et al 2003). Further studies are needed that gain access to the perceptions of people affected by dementia to hear their voices and understand their past experiences. This learning could help us understand how to provide the right services to better support them alongside their natural supports.

The confidence gained from this process leaves the researcher with more questions and the urge to go back into the field to have them answered with the time to analyse more fully.

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