



Being central to decision making means I am still here!: The essence of decision making for people with dementia



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ABSTRACT

The ability to make choices and decisions, and to have those decisions upheld, is central to self-determination. For people living with a diagnosis of dementia, however, it can be difficult to remain involved in decision making. While many studies show that people with mild or moderate dementia have the ability to participate in decision making, there are also indications that the attitudes of those around them, including health professionals and family carers, can sometimes be a barrier, and there is generally little understanding about the nature of decision making for this population. This small pilot study draws on van Manen's approach to phenomenology to explore the *essence* of decision making for people living with dementia. The findings highlight the importance of remaining central to decision making, and the key role that subtle support from carers plays in enabling this.

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Introduction

In Western democracies, the concept of personal autonomy is central to social and political discourse (Sherwin & Winsby, 2011). Autonomous individuals make choices and decisions about their own lives, and have the right to have those choices respected by others. The right to make one's own decisions is fundamental to biomedical ethics, and an important aspect of person-centred care (Edvardsson, 2008). While often the discussion around autonomy and respect for a person's right to choose focuses on 'big ticket' ethical decisions around life and death, everyday decision making also plays a vital role in maintaining one's sense of self and identity, and research has demonstrated that there is a relationship between involvement in decision making, sharing preferences and opinions, and quality of life (Clark, 1988; Lawton, 1991; Wetle, 1991). Kitwood and Bredin specifically flag agency as a critical aspect

of dementia care, arguing that, "if a dementia sufferer [sic] keeps a sense of agency, and manifests this even in the smallest actions, there is good reason to postulate that he or she is in a state of relative well-being" (Kitwood & Bredin, 1992, 238).

When an individual has a diagnosis of dementia, decision making becomes somewhat of a grey area. For health professionals, carers and family members, there are conflicts between maintaining the autonomy of the individual with dementia, while also ensuring that their health and wellbeing is not compromised (Whitlatch & Menne, 2009); that is that they do not come to harm (non-maleficence). Reflecting this concern, a large portion of the literature focuses on issues of legal capacity or competency in individuals with cognitive impairment. Authors typically focus either on ethical issues surrounding decision making capacity (Brody, 2005; Hughes, 2010; Nelson, 1994), or ways to assess capacity (Grisso & Appelbaum, 1998; Kapp & Mossman, 1996; Marson, Schmitt, Ingram, & Harrell, 1994; Willis et al., 1998). There is also a body of literature that addresses whether people with dementia are able to give consent to participate in research, and how this consent might be obtained. While it is acknowledged that the perspective of the person with dementia is of vital importance (Cotrell & Shulz, 1993; McKeown, Clarke, Ingleton, & Repper,

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2010), the issue of establishing informed consent to participate in research is of some concern (Beattie, 2009; Cacchione, 2011; Cubit, 2010; Mayo & Wallhagen, 2009).

In addition to the theoretical work, there is also a large body of empirical research examining the decision making capacity of individuals with dementia. While the literature suggests that even mild dementia has a detrimental effect on an individual's ability to make decisions (Lui et al., 2009), and that decision making ability decreases with the severity of the dementia (Hirschman, Xie, Feudtner, & Karlawish, 2004; Karlawish, Casarett, Propert, James, & Clark, 2002), it has also shown that cognitive impairment is not uniform (Kapp & Mossman, 1996), and that people with dementia may be capable of making choices about many aspects of their care, even if they are unable, for example, to decide how their finances are to be managed. In fact, Kim, Karlawish, and Caine (2002) in their meta-analysis of empirical studies examining the decision making abilities of older people with cognitive impairment, found that, overall, the literature reinforced the theory that a diagnosis of dementia does not imply incapacity. More recently, Menne and Whitlatch (2007) found that a number of factors impact on a person with dementia's decision making involvement, including age, gender, education level, a nonspousal caregiver, a more recent diagnosis, and a greater value placed on autonomy. Feinberg and Whitlatch suggest that persons with mild to moderate cognitive impairment are still able to "respond consistently to questions about preferences, choices, and their own involvement in decisions about daily living, and provide accurate and reliable responses to questions about their own demographics" (Feinberg & Witlatch, 2001, 380). Furthermore, Hirschman et al. found that the majority of individuals with dementia in their study wanted to participate in decisions about their treatment and care. "Would I? I jolly well better!" one participant emphatically responded (Hirschman, Joyce, James, Xie, & Karlawish, 2005, 385).

Despite strong indications within the literature that people with dementia are willing and able to participate in decision making, participation is often denied, sabotaged or tokenistic. Tyrell, Genin, and Myslinsk (2006), for example, in their qualitative study of French older people with dementia, found that: (a) participants were dissatisfied with the level of information provided to them and the degree of communication by health professionals; (b) felt that there was not adequate time given to them to make a decision, and (c) felt that opportunities to express themselves were extremely limited. This left participants feeling 'unheard' by both medical professionals and caregivers and unable to make informed choices with which they were happy. Several other authors have highlighted the fact that decision making involvement of individuals with dementia, and indeed, older people in general, is often curtailed or ignored (Davies & Nolan, 2003; Nay, 1995), particularly when making the decision to move into a residential aged care facility (Johnson et al. 1994), or when making decisions about sexuality (Tarzia, Fetherstonhaugh, & Bauer, 2012).

While there are a number of descriptive studies examining decision making for people with dementia, none of these utilise a phenomenological perspective. Tyrell et al. (2006), for example, conducted semi-structured interviews with participants based on Frossard, Boitard, and Jasso-Masqueda's (2001)

freedom-of-choice interview schedule. Horton-Deutsch, Twigg, and Evans (2007) also used semi-structured interviews, focusing on the process of how people with dementia made, and continued to make, health care decisions; however, the data was combined with a larger quantitative study to give an overall mixed methods approach. None of the existing research delves into the *meanings* of decision making for people with dementia. Phenomenological studies, following van Manen's (1990, 1997a) can provide this insight into the decision making process. Interpretive¹ phenomenology seeks to go "beyond the mere description of core concepts and essences to look for meanings embedded in common life practices" (Lopez & Willis, 2004, 728). Phenomenological methods have been used in a number of studies on dementia, and provide valuable insights into the experiences of people who live with it. Clare (2003), Clare, Rowlands, Bruce, Surr, and Downs (2008) and Pearce, Clare, and Pistrang (2002) have extensively investigated the experiences of people living with dementia in residential care; coping with the onset of dementia; and managing the threats to self that a diagnosis of dementia can present. Phinney (2002) focused on fluctuating awareness and the breakdown of the illness narrative in people with mild to moderate Alzheimer's disease. Langdon, Eagle, and Warner (2007) examined how the reactions of others can have a profound effect on the lived experience of an individual with dementia. More recently, De Witt, Ploeg, and Black (2009, 2010) used a phenomenological approach to explore the experiences of older women with dementia living alone, and MacRae (2010) combined phenomenology with symbolic interactionism to examine the effect of an Alzheimer's disease diagnosis on participants' sense of identity. In an Australian context, Nay (1995), used a hermeneutic phenomenological approach to explore nursing home residents' perceptions of relocation. On the other hand, Kordes (2009) has explored the phenomenology of decision making, but not in the context of dementia or aged care.

Clearly, a gap exists in the literature with regard to understanding the essence of decision making for people with a diagnosis of dementia. Essence, in this context, refers to the true nature or quality of a phenomenon (van Manen, 1982), something universal that "makes the phenomenon what it is" (van Manen, 1990, 107). Existing empirical research into decision making for individuals with dementia explores issues of capacity, and the ability to make decisions, but does not provide insight into what decision making *means* to them or explore the lived experience of how their diagnosis impacts on the decision making process. This small phenomenological study provides some initial insight, and contributes towards a deeper understanding of decision making that will hopefully inform future research in this area.

Aims

To illuminate the essence of decision making for people living with a diagnosis of dementia.

¹ Interpretive/interpretative are used interchangeably in this article according to the specific reference cited but are accepted to have the same meaning.

Methodology

Participants

Six individuals (four women and two men) living in the community and aged between 54 and 78 years participated in the study. All had a diagnosis of dementia. Time since diagnosis ranged from 1.5 years to 16 years (one participant could not remember the time since diagnosis, but said that it was “not long”). Two participants resided in the state of Victoria, Australia, and were recruited by responding to written information about the study posted by the Victorian branch of Alzheimer’s Australia to its members. Four participants were recruited through a national dementia network. These participants lived in the states of Queensland ($n=2$), Tasmania ($n=1$) and Western Australia ($n=1$). The only inclusion criteria were that the participants needed to be able to provide informed consent to participate in the research (participants requiring proxy consent were not eligible) and be able to engage in an interview. Given the complexity and problematic nature of capacity to consent, central to this research on decision making it seemed prudent that we only include in the initial work those people with dementia who were able to provide their own consent.

Ethical considerations

As with any research project involving individuals with dementia, there were ethical concerns surrounding the participants’ ability to consent to being interviewed (Beattie, 2009, Cubit, 2010, Mayo & Wallhagen, 2009). However, although dementia is associated with difficulty in reasoning ability, thinking about abstract issues and reflecting on the meaning of issues, individuals with early to moderate dementia are known to retain the capacity to make some judgements and decisions about the future (Claire, Rowlands, Bruce, Surr, & Downs, 2008) and are usually still able to verbalise and maintain an effective span of attention. This was found to be the case in our study. Furthermore, all participants lived in the community and were still making decisions about what they would or would not do on a daily basis. The decision of whether or not to participate in the research was no different to any other decision. Additionally, participants had already made a decision to actively respond to the invitation to participate, indicating that they understood the project and were willing to contribute to it. Approval for the study was received by the university’s human ethics research committee (approval number 11-046).

Interviews

Interviews were conducted between October 2011 and April 2012. The two Victorian participants were interviewed in person in their own homes, as they were located in the same state as the researchers. Due to logistical and budget constraints, the four participants living in other states were interviewed by telephone. Before commencing each interview, the researcher ensured that the participant understood: the research; its implications to them; what was to happen to their data; and how the information provided by them would be kept confidential. The interviews began with the open-ended question: “Can you give me an example of a time when you were involved in making a decision and talk me through that

experience?” This question was then followed up with additional supporting questions such as: “How did it feel to make that decision?” or “What was important about that decision?” in order to encourage the participant to expand on their experiences. The aim of each interview was to enable the participant to describe decision making as they experience it. If the participant became side-tracked or distracted, they were gently prompted to return to the topic at hand. All the interviews were digitally audio-recorded and later transcribed verbatim. Interviews lasted between 20 and 60 min.

Although all six participants were happy to converse at length with the interviewer, the two longest interviews were those conducted face-to-face. It was considerably easier for the interviewer to establish rapport with the subjects encountered in their own homes, as the participants were able to chat about things around the house (e.g., pets, furniture, the garden) as a way of maintaining the flow of conversation. Both participants offered the interviewer a cup of tea after the interview, and even freshly-baked cake in one case, which positioned the whole experience as an informal chat rather than an academic exercise. Furthermore, participants were able to physically show the researcher objects they were talking about – for example one participant showed the researcher her diary in which she recorded daily information. This gave the researcher a first-hand understanding of the importance of the diary for this participant, which would not have been possible over the phone.

For future research, we would definitely recommend the use of face-to-face interviews, however, if it is impractical or impossible, the telephone interview is a perfectly acceptable alternative. We did not encounter any problems with using the telephone for this study, and although little research has been conducted into the efficacy of telephone interviews for people with dementia, Mason and Wilkinson (2002) have concurred that it can be “effective and potentially empowering” (203) as long as the person with dementia is comfortable with using the telephone and the interviewer is able to listen attentively and put the participant at ease.

Data analysis

The interview texts were analysed according to (van Manen’s, 1990, 1997a) phenomenological approach, which has been described as containing elements of both descriptive and interpretive (hermeneutic) phenomenology (Dowling, 2007). van Manen states that “phenomenological text is descriptive in the sense that it names something and hermeneutic text is interpretative in the sense that it mediates” (van Manen, 1997b, 26). This approach enables the researcher to “transform personal meanings and experiences from interview texts into disciplinary understandings” (Thomé, Esbensen, Dykes, & Hallberg, 2004, 401). Although all forms of phenomenology seek to understand phenomena as they are lived, van Manen’s approach particularly recognises that “the practical nature of the...lifeworld demands [that this form of inquiry] not convert into armchair philosophising or abstract theorising” (van Manen, 1990, ix). In other words, by following van Manen, the outcomes of the research will hopefully inform the real world of decision making for people with dementia.

The interview transcripts were read and re-read multiple times by all members of the research team, moving back and forth between what the data in each line was saying and an

understanding of the whole context. After each transcript was read, the essence of decision making for that participant was summarised before moving on to the next participant's interview. During this continuous process of reading and summarising, themes and subthemes were identified that were common to the participants. This formed the basis for what Lopez and Willis have described as a "critical understanding of the experience" (Lopez & Willis, 2004, 732) of decision making with dementia. Since van Manen argues that the researcher's own life experience, or what they know, cannot be ignored or forgotten (van Manen, 1990), the meanings described below are a blend of "the meanings articulated by both participant and researcher within the focus of the study" (Lopez & Willis, 2004, 730).

The essence of decision making

As will become apparent, the true essence of decision making for people with dementia, as one participant said, is feeling that "I am still here!" This essence is comprised of a number of conflicting attributes: subtle support versus taking over; hanging on versus letting go; and being central versus being marginalised or excluded.

Subtle support versus taking over

Participants recognised that support would be required as their dementia progressed, but appreciated it when that support was provided in a subtle way, allowing them to still feel in control. Subtle support involved sitting down with the person with dementia and establishing a plan, making suggestions and forming strategies that would enable them to do as much as possible independently.

I do the shopping, and my wife does these beautiful lists and they're in order of where everything is in the shop. (Participant 3)

My daughters didn't take over, and they didn't just assume that 'Mum can't do this anymore'. They sort of, just wanted to see where I was comfortable in how much stuff I did want, and what I was capable of doing myself... They allowed me to still say, 'Yes this is okay, and this is what I'm comfortable with and yes, I can still do this' and it worked out really well. (Participant 2)

Checking how the person with dementia was coping and whether they were still safe with decisions was deemed to be acceptable, but being authoritative or treating the participant like a child was not:

They [daughters] will come driving with me even now and then just to see how I'm... even though I'm saying I'm doing fine... but they will just come for a drive with me to see how I'm faring, to see if that is still doing well. And so it's just things like that, subtle, not in my face saying, 'Oh Mum how are you going with your driving? Should we be concerned?' (Participant 2)

Strategies that allowed participants to do things in their own time, that kept them feeling productive, useful and

active, were seen as very helpful. One participant's wife had created a list of possible tasks that needed to be done that day, and the participant was able to make his own choices about which tasks to attempt and when. Restricting the number of possible decisions for the participant was seen as a useful strategy, as he admitted that without specific direction he often became sidetracked and lost focus. Having the tasks listed and the list accessible as a reminder reduced his stress level, as he pointed out, "I don't have to worry whether [my wife] wanted that done, or this should've been done" (Participant 3). Furthermore, all the tasks on the list were necessary to maintain the property, so the participant was always engaged in valuable, productive labour, and not "just sit[ting] around the house" (Participant 3).

This notion of being useful and being able to make a contribution was an important part of decision making for participants, and being in an environment that allowed them to contribute built up confidence and self-esteem. This was evident in the following example of a participant who, with good support, was able to continue his sailing hobby, something very important to his quality of life and sense of self:

I think as long as I can make decisions, I can still go out and sail a boat ... Sailing is all about making decisions ... If you're racing a yacht, just about every 3 minutes you've got to make a decision. Now, I have got some fantastic backup on my boat, who are always going to turn around and say 'Come up!' or 'You're not on the mark'... It gives me the confidence to get out there and try and win races. (Participant 3)

Central to the confidence this participant felt was the knowledge that his sailing companions would not be afraid to speak up if he made a wrong decision or was not performing as his 'usual' self. This notion of support as 'backup' represents one of the key differences between subtle support and taking over. The person with dementia needs to know that help is available if they require it, but it needs to be on their terms.

Additionally, the participants needed to feel as though there were still expectations placed on them, that they had something to add, as this indicated a prima facie assumption that they could still contribute to decisions. Feeling that they were required to keep working towards goals and initiate decision making while they were still able was seen as important. Once again, this worked most successfully within a framework whereby the carer helped with the aspects that were too difficult:

My wife doesn't mollycoddle me or anything like that. It's the other way around. You know, 'Why haven't you cooked the tea today?' (Participant 3)

I tend to sort of initiate and ask and talk about it [a decision to install solar panels] a lot, and be the one pushing for it, but then getting [my husband] to do some of the emails because it requires calculations and things, of what kilowatts and stuff. (Participant 4)

Similarly, enablement and 'having a go' were seen as empowering and vital to the participants:

[My girls] might be too protective. I prefer to go with [my husband] who will enable me rather than disempower me. (Participant 4) Let them have a go! Don't try and take over. Let them have a go, and sort of talk to them and say, 'That's the way you're doing it, but why don't you try this?' Don't push things onto them, but just let them....let them decide and then talk about it. (Participant 5)

Attempts by family members, carers, or medical professionals to take over decision making were viewed negatively by participants for a variety of reasons. For two of the participants, both of whom were in their seventies, the decision for them to stop driving had been made by someone else with little or no discussion, and this curtailment of their freedom caused the participants some resentment. As one participant said:

At this stage the only thing that's been upsetting me is my car.... Because my son's taken it and he lives up in the country and he's not giving it back. And that's not nice, you know. (Participant 5)

For others, attempts to take over decision making caused feelings of frustration and a desire to rebel against the constraints being placed upon them. One participant, for example, had clearly stated that he did not want home assistance, as the agency staff could not come at the desired time. Despite this, his wife went ahead and booked the service, which annoyed him greatly. Another participant, who described herself as always having been a very forthright and decisive person, explained how she would feel if her decision making were taken over:

My independence is really important to me, and I know if someone came in and started telling me how I should run things or do things, I think I would certainly retaliate and not conform to anything they would want to do. (Participant 2)

Maintaining a sense of control over their own lives was clearly very important to the participants. While they were happy to accept some support and assistance, they wanted to be the ones making the final decisions, and resented interferences that overstepped the mark. The best form of subtle support for the participants seemed to be when carers were strongly present as 'backup'. This allowed the participants to make their own decisions with confidence that someone would be there to rescue them if they made a mistake.

Hanging on versus letting go

The participants were aware of what their diagnosis meant in the long term, and most of them were pragmatic in their approaches to the future. As one participant commented, "I know things will keep falling off, and stupid things will happen" (Participant 3). At the same time, however, the participants wanted to hold on to their decision making abilities for as long as possible, which is consistent with other phenomenological research in this area. Clare (2002), for example, found that 'holding on' and 'fighting' were central themes amongst the participants in their study on coping with the onset of Alzheimer's disease. This tension between hanging on and

letting go required continuous renegotiation and compromise on what decisions to relinquish, and which to hold on to.

Driving was a particularly contentious subject for the participants. Those who could still drive wanted to be able to do so for as long as possible, although they did acknowledge that there were limitations to their abilities:

I'm really still quite independent. I still drive, although, by the way, I wouldn't drive today! (Participant 1)

[If I couldn't drive it would be] very bad I think, yeah, very bad. I would've had to deal with that. I'm not sure how. Having passed [my driving test] means I can drive if I want to. Which isn't that often – might be once a fortnight or once a month. But it's something there that I can still choose to do. (Participant 4)

Several participants had developed strategies that enabled them to continue making decisions and stay independent by compensating for their cognitive impairments. One participant had a diary in which she wrote everything that had happened during the day, and everything that was coming up.

It jogs the memory all the time. 'Oh I remember we had that heavy rain', and 'The cleaning lady came'. If I didn't have this little book, I'd be lost. It's what keeps me going because I know that it's all in there. (Participant 5)

Others used alarms and reminders on their calendars or mobile phones, and ensured that important decisions were made immediately, instead of putting them off until later:

I don't put off many things now, because I'm concerned that I'll forget about making important decisions... I will try to deal with as much as I can now, or I'll make sure that there are things set up to remind me like a phone alarm, or something, to make sure I keep on top of it and I don't forget. (Participant 2)

Maintaining independence was an important part of 'hanging on' for the participants. In some ways, staying independent was a way of proving to themselves, as well as to others, that they were still capable individuals.

I was walking through some very, very remote scrub on the edge of the inlet there, on tracks that probably only get walked once or twice a year...I've been wandering for hours there and back. A decision I made, I'm going out there, I'm OK. (Participant 3)

I've been by myself for....my husband died in 1974 and I've been by myself ever since. With my kids back then, and now I'm by myself. It's just the way I've been. (Participant 5)

I do everything! I like my house, I like doing my own housework! I do my own washing! I do my own ironing! (Participant 6)

Despite their best intentions, participants were forced to acknowledge their limitations and 'let go' of some decisions they had previously been in control of. This decline in decision making ability was seen as an unpleasant but

inescapable aspect of the dementia trajectory. One participant, for example, who had previously had a very successful career in a job that involved being able to remember details and influence those around him, had found it very difficult to reconfigure his self-image as a person who now needed help with decision making:

I'm slower [at making decisions]. And I'm slower on purpose. And I talk to more people about it before I would do it. I mean...I'm quite dependent on my wife...because I can't do most things independently any more. (Participant 1)

I never would've had to have written things down. I would've been able to just say 'Come on! We're doing this today!' I would know everything, but I don't now. (Participant 5)

For those participants who had previously been very self-reliant, admitting that they needed help, and accepting that help, was sometimes very difficult.

[My daughters] put in their suggestions and we then put them all in place, which was really hard because I had to then tell the girls the things that I'd been doing, and what state my financial situation was in. So it was a really difficult time for me to have to admit where I was, and that I needed help. (Participant 2)

We talk about things that need decisions. I don't do anything unless...especially now, I ask [my husband], 'Is this alright to do this?' and he'll say 'Yes, you do that' and it bugs me but I have to live by that. (Participant 6)

If they did not allow others to become involved in their decision making, however, participants recognised that they would not be able to obtain the kind of support that was integral to maintaining their independence. In other words, they were forced to relinquish some control in order to keep it. For example, Participant 3 had accepted that he needed to listen to others if he was to continue sailing:

I probably take more advice than I used to. I used to be quite bombastic about it: 'No, we'll put up number 2 and that's it!' Now, it's: 'Well I think number 2, what do you reckon lads?' (Participant 3)

For one participant, letting go was a matter of prioritising her good health and ability to continue to make decisions in the long-term over a hard-earned position on the board of an international dementia organisation. While the decision was a difficult one that she regretted, she stated that she was “totally overwhelmed and exhausted” (Participant 4) and that relinquishing her position was a necessary sacrifice in order to maintain her cognitive abilities. In this instance, letting go became a vehicle for hanging on rather than an alternative to it.

Feeling central versus feeling marginalised and excluded

Participants emphasised the importance of feeling central to decisions that involved them, and strongly resented situations where their input was ignored, or where they felt marginalised or excluded from decision making.

When the guy [from the agency] came out he basically didn't talk to me, he was talking to [my wife]. And I got quite upset, and I told him so. And he told me something like, well that's what they do, and I said, 'Well that doesn't meet my needs', and 'I'm the customer', and he said 'No, she's our customer' and I really got quite angry. (Participant 1)

For one participant in particular, the experience of being excluded had been an extremely painful one:

I thought [my son and daughter] had come to see me. I was so excited, made them a cup of tea, because they don't come very often. My other daughter always comes, but they don't come very often. And they had this plan in mind but they never told me what they were going to do. They were going to take me and put me in a nursing home. They never mentioned it to me. I just found that out when they'd gone when I saw they had my sponge bag...ready to take. (Participant 5)

Feeling excluded from decision making had occurred in a variety of contexts for the participants, from family members through to health care professionals, and even representatives from dementia organisations who, as one participant noted, “should know better” (Participant 1). Being ignored made the participants feel insignificant, as though their identity as a person was under threat, and that they were nothing more than a “piece of wood” (Participant 5) who should “just go home and disappear” (Participant 4). On the other hand, one participant commented that being central to decision making meant that:

I feel more settled and okay in myself. That I'm still doing things and capable. To have still some independence in there. That I am still here, and I do have a say, and I'm not just a person with dementia and ignored, and that everybody else knows more than me. To still understand that there is a person there, and being aware of what stage I'm at, and what I can still input and allow that to happen. (Participant 2)

This sentiment was reinforced by Participant 1, who emphasised the need for people with dementia to be acknowledged and consulted. He expressed his irritation when “People talk about me, around me, but don't talk to me.” (Participant 1)

Surrounding oneself with people who made an effort to involve the person with dementia in all things was seen as key to feeling central to decision making. Maintaining close family relationships and trusting friendships was a part of this process, and participants expressed pity for those who had to do it on their own.

Certainly the friendships I've built up over the years have been a magnificent help. Without those people I think it would be a lot harder. I know it would be a lot, lot harder. I mean it's Friday and the boys will pick me up and take me to a 5 star restaurant today. They will. (Participant 3)

I feel like I'm part of the decision, even though I know probably now I'm not contributing a great deal, at least I feel as if I'm part of the decision. And that's very, very important. So I feel enabled and empowered, even though each year goes by I'm less participating, at least I feel as if I am. (Participant 4)

Feeling central to decision making was even seen as a way to combat dementia. Participants spoke of needing to continue to set challenges and goals, and to keep making decisions, even when it was difficult or tiresome to have to do so. As one participant stated, “Half of me feels like, why not just tell me what to do? But then, I think I’d go rapidly backwards if that what it was like.” (Participant 4)

Conclusion

This small pilot study provides a valuable insight into the essence of decision making for people living with a diagnosis of dementia. Although participants were aware of what the future might hold for them, they retained a desire to remain central in decision making that affected them for as long as possible. This included planning decisions for when they knew it would be harder for them and more decisions would be made by others. A support that was subtle and assisted them to make their own decisions was greatly appreciated. When ‘carers’ took over and support was forced upon them reducing or removing their role in decisions it left them feeling marginalised and excluded. Although the number of participants was small, their voices resonate strongly within the data. For the participants in this study the essence of decision making was to *hang on* for as long as possible, enjoy *subtle support* that enabled a feeling of worth. Being and remaining *central to decisions* that affected them was a way to affirm: I am a person! I am still here!

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