

Patient & Carer Perspectives of life transition in Alzheimer's Disease:

A study of how patient and carer narratives from life experience describe their perceptions of disease progression

Rick Harris, Emma Chilvers, Amanda Forsheo and Andrea Ingrisich

Abstract:

This report summarises research conducted in 2009, with the objective of understanding how patients and their carers living with Alzheimer's Disease described the challenges and experiences of everyday life and decision-making, as the patient's disease progressed.

Our ambition was that such insight could support ethical decision-making, grounded in the voice of both patients and carers.

The research reported in this publication was commissioned and funded by Pfizer in 2009. Pfizer granted permission for the information from the research to be used freely by Customer Faithful for the purposes of this publication. Pfizer has not been involved in the authorship or review of the content of this publication.

This research is being published online from the first time on 21 September 2021, which coincides with World Alzheimer's Day. We are grateful to Pfizer for permission to publish this report.

Introduction

This study concerns Alzheimer's disease - the most common cause of dementia, affecting around 417,000 people in the UK¹.

For over a decade now (2009), the Department of Health (DoH) has described the importance of seeking out and responding to patient-led accounts of their own healthcare. Indeed, the 2001 NHS Plan aimed "to create a patient-centred NHS.....where the voice of the patient is heard through every level..... acting as a powerful lever for change and improvement."

The aims of this study are very much in line with such an ambition, seeking to explore the perspectives and experiences of carers and patients in regard to facing and dealing with transitions in lifestyle, during the progression of Alzheimer's disease.

In addition, we were seeking to organise this insight into a framework of themes

¹ Source: Alzheimer's Society - [NOTE, this is now quoted at 520,000](#)

that could help improve understanding and decision-making.

Furthermore, we sought to frame our findings in the context of potential ethical dilemmas, where the perspectives of life events may differ between patient and carer, and which may impact decision-making activity. The ambition was to serve future patient and carers by providing visibility and structure to such issues.

Methodological Considerations

Earlier studies have indicated that people in the early and even moderate stages of dementia are often capable of expressing meaningful opinions about their quality of life.²

Therefore, we felt that a qualitative research method, conversational and open-ended in style, would offer great depth and richness, especially in terms of language used and examples described.

Method

The method used was interpretive phenomenological analysis (IPA), chosen because of its primary focus on the subjective life experience of the participants through a close examination of their individual account of living with Alzheimer's disease. Given the depth of the IPA analysis, there was a practical consideration given to the sample size. IPA challenges the traditional linear relationship between 'number of participants' and value of research. Indeed, the principle author of IPA research cites 10 participants at the higher end of most recommendations for sample size (Smith et al., 1999). Therefore, it was felt that 12 participants was a suitable sample size in line with methodology recommendations.

The study received ethical approval from the National Research Ethics Service³.

Participants

Participants were recruited with the assistance of GP referrals and Dementia UK. Six patients were recruited in this way, as well as their carers, whose narratives would also be studied. The patient inclusion criteria was for a) each patient to have a diagnosis of Alzheimer's Disease, b) the capacity to consent to and communicate verbally in an interview situation. In addition, an identified family carer was also available to be interviewed and support the patient interview where requested. A

² Brod, Stewart, Sands & Walton, 1999; Mozley et al. 1999, Tyrell, Genin & Myslinski, 2006

³ NHS REC Reference No. 10/H0716/37

GP validation letter was used to confirm the patient inclusion criteria.

Procedure & Data Collection

The study consisted of an interview with each participant (typically 60 minutes), either individually or as a pair, dependent upon the care needs and wishes of the patient.

Participants were interviewed in their own homes, in accordance with their preference, with each interview audio recorded. The recordings were then transcribed and analysed to explore the variance and concordance of views across participants, to seek to identify key themes, and to triangulate with themes identified within earlier secondary research.

Results

Patient & carer characteristics

The six patients were aged between 51 and 81 years, and consisted of five men and one woman. In each case, the carer was the wife or husband of the patient, with all participants still living at home. Carer ages ranged from 50 to 79 years.

Our findings are presented here as a series of ethical questions that participants described, using their stories and accounts to identify ways in which they dealt with them.

Early Signs

Should people who potentially have Alzheimer's and who are in denial / avoidance be encouraged/made or forced to take action?

The tipping point for confronting and taking action over disease symptoms varied across each individual, but included concern for the other, own safety, job considerations and disruption to lifestyle. For some spouses or other family members, such action was often felt as a significant act of disloyalty in the relationship and sometimes required a degree of inventiveness to achieve action. However, although difficult, no one in our sample regretted taking action in hindsight.

We found evidence of consequentialism – i.e. that there was more to be gained than lost, and that careful and positive phrasing could be successful in encouraging consensus to take action.

"I was making not huge, but minor mistakes and things like that. I felt to be struggling a bit anyway, and then my daughter noticed something.... Perhaps it was about my balance but anyway my daughter said "We think there is something not quite right, it

would be a good idea to just check things out. There is nothing to lose and quite a lot to gain.” [Interview A, Patient]

Whilst some carers described feeling guilt over seeking help without the patient’s consent, they justified their eventual action in terms of a perceived responsibility as a spouse or loved one to act in the patients’ interests.

“It got to a stage where I can't remember particular details but he wasn't eating well, he wasn't sleeping well, he was forgetting things very, very quickly. I decided that I would share this with our three daughters. That was the hardest part of it "I think there's something wrong with dad, help"..... I also felt very, very disloyal talking about him behind his back. [Our daughter] went to our GP and said "I don't like the look of my Dad". She went in desperation. [Interview D, Carer]

There were also instances where action was taken by the carer in order to gain more informed judgment by seeking the opinion of a doctor. Carers reported a sense of relief upon reassurance from the doctor that they had done the right thing and were acting in the patient’s interests, if not directly upon their wishes.

“In the end it took quite a bit of thought I went to the doctor myself..... I felt very guilty really about going behind his back but he said I had done absolutely the right thing to come and talk.....” [Interview A, Carer]

It was apparent, even in these early stages of recognising health problems and consequences of the disease onset, that a transition was beginning – of the carer taking more responsibility for the safety and physical needs of the patient, and an emotional shift, where trust and openness within the relationship may have to become less balanced than before.

How to balance the distress of diagnosis with the benefits of early treatment and planning?

Participants expressed the impact of receiving the diagnosis across a range of emotions, including shock, disbelief and anger, but also relief and personal resolve.

A number of patients and carers told of a sense of unpreparedness – the shock of identifying themselves with a condition they perceived as affecting elderly people, and the resultant consequences to their established activities.

“Well you could have knocked us down with a feather because until that point, Alzheimer's had never been mentioned either by the GP or us, it just wasn't on the radar at all....I had this image that Alzheimer's is the domain of the elderly --- I was at that time, the only person I knew with Alzheimer's below the age of 70. You feel as though you are the only one.” [Interview C, Patient]

“We were devastated to get that news. The only positive note you can take from that is for all that time it is probably actually worse leading up to the diagnosis because your life is just in turmoil because you don’t know what to do. You don’t know whether to sell, stay, [not] work or go to work.” [Interview B, Carer]

“It has hurtled us into old age.” [Interview A, Carer]

Each of these comments was from a younger, pre-retired demographic of patient (and carer). They described diagnosis as bringing uncertainty into their lives, due to the lack of a predictable timeline for disease progression.

These comments also reflect how diagnosis brings about an unbalanced transition – the suddenness of ‘hurtling’ into retirement, the lack of same-generation friends in the same position, the need to make swift adjustments in life that were otherwise perceived as decisions made slowly over time.

However, some participants found the delivery of a diagnosis could unlock access, in terms of providing clarity on the condition to patients, access to treatment and a spur to encourage effective planning

[regarding the diagnosis] “Tremendous relief. I knew there was something wrong with me; I was feeling anxious, feeling I couldn’t keep control with things. Things weren’t going right but I couldn’t think why I was getting things wrong.” [Interview D, Patient]

“We are doing Power of Attorney and renewing our Will at the same time for both of us --- we haven’t made one for 30 years.” [Interview C, Carer]

“So we went through the whole gamut and eventually landed up with a psychiatrist who said “I am glad you came when you did because I think it is early stages and you will benefit from [Drug X] for five years I can say from this point.” That was just over three years ago and we said “Thank you very much.” He did in fact psychologically or physically did immediately benefit from taking [Drug X].”

There was a sense that, whilst a diagnosis could confirm fears that both carer and perhaps patient were conscious of, it also brought an ‘official’ result – one that enabled treatment actions or made planning actions easier to start.

When should friends, employers and other stakeholders be told about the diagnosis?

Whilst early fears may well be kept secret, on diagnosis, most patients in the study chose transparency of some kind. Carers in particular commented that being open and truthful with others avoided the need to invent reasons, which carried its own stress.

“A couple of people had expressed concern to me about his memory but as soon as we got the diagnosis, he came home and got on the phone to our children, our friends which was tremendously helpful for me because it meant I wasn't having to make excuses for him or cover up for him if he was forgetting stuff.” [Interview E, Carer]

“Just tell people, and then it is up to them whether they choose to understand or not. Because you have got enough burdens without trying to hide things I think. [Interview A, Carer]

Whilst participants suggested that telling friends was an optional choice, they perceived informing employers as mandatory. This was in part due to the need to pursue ill health redundancy, but also out of concern and respect for colleagues.

Immediately I asked for some time with her boss because obviously we then had to go through the process of making her redundant through ill health, which he agreed to. [Interview B, Carer]

“The only people who knew at the school, because I had to tell some people obviously. I told the senior leadership team and the office staff and they did a lot of covering for me in the sense of fending off staff concerns because staff were obviously a bit spooked by what was going on.” [Interview C, Patient]

Nevertheless, patients and carers had some negative experience after telling some friends. This was largely exhibited through friends avoiding contact with the patient – something that patients, carers and their families were not always prepared for. Respondents either stated openly or implied that they saw this as confirming who their ‘real friends’ were.

“I could read too much into this but there are one or two friends who since they have known what we are dealing with, dealing with the Alzheimer's, they have distanced themselves. Whereas others have been no change.” [Interview C, Patient]

“Her, and my attitude, right from the start of diagnosis was that we know there are a lot of people hide it but we don't, we said it was not her fault, it was nobody's fault. This is what she has got and we will be up front about it..... Not that we go running round telling everyone either.” [Interview B, Carer]

“I was determined that once I was diagnosed for definite with this I sat down with each and every one of my kids and I told them on my own didn't I? Purely because I didn't want any nods or winks “What's going on with Dad?” Friends when I announced, not announced but when I said I had got Alzheimer's I lost 75% of my friends.” [Interview F, Patient]

“Initially people found it I think quite difficult and I noticed that the number of people who stopped speaking to me because they didn't know how to cope with it.....it does spread and the people who do want to talk to us will talk to us and people who can't cope with it won't and it will sift the people from the others.” [Interview A, Patient]

Throughout these aspects of informing others, there was a desire from couples for their changed circumstances to be understood and accepted. This was not about seeking sympathy, and usually not even an expectation of direct support. Instead, the patients and carers felt that part of a successful transition was to 'level' with people who matter (close friends, family and employers). It was implied, but unspoken, that there was no going back from such communication, and that they could not control how shared information was spread further. The most consistent trend of all was that such information sharing was most appropriately done as soon after 'official' diagnosis as possible.

Everyday Living

How do you respect choice and autonomy in everyday living for the person with Alzheimer's?

This ethical challenge reflects the quandary often cited in medical ethics – balancing autonomy (that people should be able to decide for themselves what they want to happen) with beneficence (that we should try to do good for the people we care for).

Carers in this study described how frequently decision-making of this kind occurred, as even small matters could cause a dilemma.

*“When he needs help, it is: when do you help and when do you stand back? There were things, that was: what we had got to learn and we **still** have to work on it. When do you help somebody if you can, do his zip up, how long does he struggle? It is simple things. By getting it wrong and then you realise you mustn't do it that way. You tell me quite forcefully if I have got it wrong. It is hard to see somebody struggling and losing skills.” [Interview A, Carer]*

This example demonstrates the dilemma that, for the carer, the support issue is easily solved from a practical perspective, but by doing so, this can receive a rebuke that the carer has acted against the wishes of the patient:

“There is a tendency I think to help too much early on and “I will do that for you dear” “Bollocks” only do it if it is asked for, is my motto. I think most people would have that view. We will ask if we have got a real problem and if we don't need it, bummer off. It sounds very rude.” [Interview A, Patient]

The motivation of the carer can be that they find it difficult not to act, as it feels that they are prolonging patient struggle as a result. The patient perceives that they will ask for help if needed, but this is a judgment that the carer is making too. Carers stated that they would override patient autonomy if necessary, especially in regard to balancing patient safety.

“He is not safe out on the roads because he has no conception of traffic, it is like – no disrespect but it is like taking an 18 month, two year old out. I have to watch him all the time. If I let go of his hand he will go across the road.” [Interview F, Carer]

In this example, our interpretation of the analogy of childcare is that carers feel supervision needs to be constant, and that they have a duty of care where unprotected environments constitute a risk.

In cases where the disease was in its earlier stages, patients themselves were conscious that their capacity to make autonomous decisions was impaired, and may require adjustment by the carer.

"I think part of my problem is that I think I can still do these things." [Interview B, Patient]

"We both want to retain our own individuality to be free and find the right balance. We don't want Alzheimer's to be predominant; at the same time I know I am dependent to a certain extent. I suppose that is the only issue really, I would hate to be completely dependent. I am to a certain extent dependent now; I wouldn't want that to increase. You know most probably better than I do what is going to happen to me, but I am keeping my fingers crossed." [Interview E, Patient]

Evidence within the fieldwork suggested that carers exercise a degree of trial-and-error, testing the boundaries of each other's ability to cope, and seeking a pattern that achieves a balanced outcome for both of them.

"I have to say to people "I know this sounds crazy but let her do it wrong first" if it is of no danger. Obviously if it is a danger she can't. If it is of no danger let her do it." [Interview B, Carer]

One way of achieving this balance was for the carer (and sometimes patients too) to try to foresee such issues in advance and defuse them before they occur. This might also include involving professional help. The justification of such action was interpreted as attempting to make each remaining day as positive and non-confrontational as possible.

"I am guarded [with patient] and it's the same with him --- I know he is guarded with what he says because of upsetting each other really, it's making the most of each day." [Interview C, Carer]

"I am not always honest in the answers I give her. I think some days she sees thru' it..." [Interview C, Patient]

"I do feel sometimes though it is like treading on egg shells because I am conscious sometimes I can upset him without intending to and it can be the simplest, something I would never dream about. I think about... I learn how to phrase questions" [Interview A, Carer]

"I got the Admiral Nurse in to tell him off about that one. She did it far better than I did, this is some years ago. She did a sort of "Well I am sure - let's look at it from every point of view. Maybe you are perfectly right and that you are safe on the roof as you

always have been, and you are not an idiot and you are quite a strong man, quite young.....but at the end of the day for some reason or other, it is worrying the life out of your wife. So how about stopping and thinking of that and not doing things quite like that so that she feels better?" [Interview D, Carer]

These accounts illustrate how a change in patient condition or behaviour (such as increased agitation, lack of awareness of environment) affects the couple. Carers take on a heightened sense of responsibility, but often seek to avoid making such ownership overt. The use of 'small talk' and non-confrontational activities can mitigate risk of arguments over autonomy, but at the cost of losing some openness. The compromise is created by and lived with by both carer and patient, in the belief that a recognition of managing both people's needs offers a better chance of a sustainable relationship.

How do you ensure the family carer gets the right support to manage the physical and emotional challenges?

There are often significant health and wellbeing impacts upon the family carer. An element of this is physical exhaustion, due to the 'always-on' nature of caring for a spouse. The support of someone like a GP, who has access to broader support services can be reassuring as well as effective.

"I actually went to my GP last week and he said [to me] "You look really tired." I said I was fine, he said "You know where the phone is if you need me, just ring me up." [Interview F, Carer]

Carers were conscious that their own health was important in supporting the patient, and this responsibility created some worry, both in their ability to stay healthy and the subsequent impact on the patient.

"I try not to think about it, because I am that much older I have got to keep fit, that is my one thing, I mustn't be ill. It affects my sleep. I still worry, I still wake up thinking "Can I cope?" when there are going to be bad times." [Interview C, Carer]

"If you look at my health record, you will see that I was very healthy up until the point of her diagnosis and since then I had one illness after another. How long do you think it is going to be before I am back in hospital when I go back to work? You have been prepared to put all this care in place. I had care in place when I was in hospital because how do you police two people, two carers and do your caring responsibilities in the mornings before you go to work and in the evenings and not become ill?" You don't even know it is happening" [Interview B, Carer]

Carers acknowledged that physical and psychological support from Social Services

and Admiral Nurses was helpful to manage this, although not all couples gained access to support immediately after diagnosis. Carers stressed the importance of having continuity of support, including an individual whom they felt they knew, and could trust for objective guidance.

“Social services was also an issue because immediately you get the diagnosis they inform Social Services. Well - we never saw them until October. She was diagnosed in the January.” [Interview B, Carer]

“The hospital, they would only send me home if I had a package with Social Services like his [patient], except they did it with a different agency” [Interview D, Carer]

“I think it is important that you get that close communication with this one person because they then can see at a glance whether you are deteriorating for instance before you can yourself. Whether you need more help than you think you do because you tend to think because it grows on you, they say to you “Fill out this form and get a benefit.” “Are you caring for him 24/7?” and you say “Well no he looks after...” “Well would he take his pills if you weren’t there?” “Well no.” “Well how many times do you have to ask him to take his pills?” “Well I don’t know but...” and you have taken it for granted that you do these little things except they are a mountain of little things. The Admiral Nurse is there to keep an eye on that.” [Interview D, Carer]

“We sat down after Christmas and we wrote down how many people we could remember that come through our front door since her diagnosis. Forty people we got to.” [Interview B, Carer]

Overall, it was clear that carers were conscious of having to take on a combined ‘health’ responsibility, in looking after the patient and themselves. Whilst respite (such as daycare or home visits) could help ease fatigue, carers highlighted the value of building trusted relationships with known individuals, beyond the service provision itself.

How do you deal with relationship changes?

There was universal acknowledgement from patients and carers within the study that the disease impacted many dynamics of their relationship, including division of chores/tasks, level of companionship, and decision-making responsibility. In particular, there was recognition that such activities were no longer handled mutually.

“I felt that I was letting you down because it had always... it had always been a 50/50 thing. After a while I realised that my skills were right down and she was actually doing bloody well.” [Interview A, Patient]

“The impact on me or anybody who is looking after somebody and especially if it is a

couple is you now have to make all the decisions. He will say "I don't know - you decide" [Interview F, Carer]

Both the patient and those around him or her felt like he or she was no longer the person they were.

"But they [friends and colleagues] were mindful that I wasn't the same person I was before and said that from time to time." [Interview C, Patient]

"I think that is one of the hardest things, not to have him as a partner anymore, that is what it feels like. Not all the time." [Interview E, Carer]

Dealing with these relationship changes involved a 'coming to terms' with the altered status, from one of equals to the carer feeling like he or she was facing some things alone, or on behalf of the patient. Success happened when the family carer was able to both honour the persona of the patient that 'was', and care for the person they have become. However, such a transition took time and practice, and caused strain along the way.

"We still have difficult times though don't we, where we get it wrong; we don't understand each other's needs. I can do things I never thought would, don't intent to make you angry but do and it's difficult trying to get inside somebody else's mind. Sometimes I do something that I think is being kind and helpful and he sees it as not an invasion but that I am too bossy. It put a bit of strain between us didn't it....." [Interview A, Carer]

This final quote emphasises the challenge of empathic understanding – to step into another's world and see what is meaningful to them. Yet, whilst difficult, participants felt this was appropriate and helped keep their situation in perspective.

"People say to me "It must be very difficult for you" and I go "Well no matter how difficult it is for me, all I have got to do is look at [patient name] and know it is far more difficult for her." [Interview B, Carer]

How do you best decide when it is time for in-home or out-of-home help if the person with Alzheimer's and family has different views?

Whilst a decision such as this might ideally be made jointly, the introduction of care typically required a range of factors to consider. Whilst both patient and carer could contribute to such assessment, it was typically the carer who made the final decision, based upon the combined needs of both people.

"He has carers twice a week, two hours, which he objects strongly to." [Interview F, Carer]

*“Believe it or not, I am quite a private man. I just don’t like strangers being sat around and just being sat in here for two hours and trying to make polite conversation”
[Interview F, Patient]*

The example above (of patient and their carer) illustrates how the carer acknowledges the dislike of in-home care by the patient, but assesses his feeling of intrusion as a necessary compromise to enable some respite for her. Despite this, the carer herself sees the level of day care as a compromise, viewing it as limited in both frequency and quality.

“Yes you do eventually get carers in and things like that but there isn’t enough respite care, there isn’t enough day care and a lot of the day care, not all of it because there is some good day care, but a lot of the day care they are so bored they don’t know what to do with themselves.” [Interview F, Carer]

Some carers described the decision to bring external carers into their home as one that was under regular review, balancing both the performance of the external carer against the changing condition of the patient and further factors such as affordability.

“I said I was not happy about having people in here for 12 hours looking after her that she doesn’t know from Adam and they have got to be here from half six in the morning till half six at night. So then they suggested live-in, because they said it is actually cheaper than having two carers.... No matter how good they are, they do come and go, they do go sick. They do take liberties if you are not on top of them.” [Interview B, Carer]

There were clear expressions from some patients that they would accept external care, less for themselves but rather if they felt their spouse needed the respite.

“Actually I am watching her and watching how well she copes.” [Interview D, Patient]

Dealing with this issue was very much one of judging combined needs and aggregate benefits for both patient and carer. Decisions were made based on assessment of multiple factors, and usually involved compromise. It was recognised that accepting care represented a loss of independence for the couple, and a degree of privacy too. Carers also reported that the effort involved in overseeing external care was significant. Therefore, when set against this range of factors, patient satisfaction with the introduction of care becomes but one factor to consider. We would suggest that carers who tackle this issue with such a ‘balanced scorecard’ approach will find it easier to arrive at an informed decision, even if the action itself remains difficult.

How to balance hygiene and carer burden with individual freedom and privacy as bladder and bowel function are lost?

The experiences of patients and carers in this study centred on the social impact of personal hygiene difficulty – the loss of privacy, dignity and freedom. Most tried to avoid situations that were likely to cause difficulties, and find alternative ways around the problem.

For some patients, the concept of an external carer (beyond spousal care) even for washing and cleaning needs was simply unacceptable, seeing it as invasive.

“They have no right to put their hands on me. My body, my rules.” [Interview F, Patient]

The carer of the same patient understands these “rules” and so focuses on trying to gradually introduce less invasive care from others as a bridging tactic.

“He won’t let anybody do any personal care whatsoever for him apart from me. So the idea is to get him used to people because he has lost his confidence that way and the trust of trusting other people isn’t there.” [Interview F, Carer]

Yet, the couple had specifically discussed a future possibility of patient incontinence, feeling that it would be easier to decide together an approach in advance, without the stress of the issue being current.

“I don’t want her dealing with me if I start soiling myself. I struggled with it, but because of that we sat down and we chatted about it, we hit it head on.” [Interview F, Patient]

Another reported issue was that of using public toilets, and the difficulties of providing support that may be misunderstood by the general public.

“It became very difficult with her using the ladies toilet and everyone thinking I was “Pervy Pete” outside the toilet door all the time because she has an issue with toilet doors, getting in and out of cubicles.... I then have to go back in and bring her out. Again I think that was probably the last time we will go out for a meal on our own.” [Interview B, Carer]

*“We have now started using the disabled toilets so that I can go in but of course she doesn't **look** disabled. Then people look at you as if to say “Why are you using the disabled toilet?” You don't want to keep getting the care out and going “That's why” or getting in arguments.” [Interview B, Carer]*

These two examples demonstrate that even early difficulties with personal hygiene, (prior to incontinence) present social and relationship challenges. Once again, the narrative from couple F suggests that the earlier and more open the planning for ethical challenges, the easier a decision can be reached as a combined judgment. The

experience of couple B highlights how social attitudes impact upon their willingness to go out in public, and that avoidance can be viewed as a better choice than normalising the issue, despite the resultant loss of freedom.

How to deal with the individual's loss of capability to make legal, financial and medical decisions?

From dealing with day-to-day administration and paperwork, through to making important legal, financial and medical decisions, the spouse or family carer had to step in and take over. Often this represented a new role for that individual within the relationship and was perceived as 'the responsible thing to do'.

I think what has happened is that she very decently and thank goodness she was prepared to do it, she took up all what you might call paperwork. All the finances and everything like that because I wouldn't have been able to cope with that. I just wouldn't have remembered what was going on and how they were fitting together. [Interview A, Patient]

[On handling money] I was good at it but not anymore so she handles that. She is very efficient you can tell, she is annoyingly efficient, well organised. [Interview E]

In doing this, the spouse or family carer often needed to develop new skills.

"It was a steep learning curve for me because in our married life it has fallen into different roles. He is great at planning holidays, he dealt with the finances and legal things and I would deal with the children things. We did help each other but we did have, you were much more expert, buying the house and things you were always the lead person in the finance." [Interview A]

Often this type of planning and decision-making addressed the needs of *both* individuals, as circumstances made them realise the importance of providing for the long term. There was a sense of 'you never know what might happen' and heightened awareness of their own mortality caused spouses and family carers to take steps to ensure they were financially and legally secure.

We are also looking at setting up Lasting Power of Attorney. So we are going through the process of that at the moment. Indeed for both of us, so rather than just for me. My situation is the prompt to do it but we are doing it for both. [Interview C, Patient]

We are doing it at the same time and the same with the will we are renewing our will because we haven't made one for 30 years. [Interview C, Patient]

Nevertheless, the subject brought home all too readily the consequences, making it a difficult topic to discuss.

We have just been to remake our wills or we are just in the process of that..... That is awfully hard to talk about and think about. [Interview A, Carer]

The need for legal, financial and medical decision-making demonstrates very clearly the inevitable shift of responsibility towards the carer. While there are differing attitudes around towards discussing these issues in advance, those that planned ahead were better able to capture patient wishes, needs and preferences. As a result decision-making becomes easier and more inclusive.

How to balance truth telling with causing distress as the individual's memory diminishes?

Family members, spouses and carers often face a dilemma over whether or not to tell the truth. When the symptoms of the disease impact the patient's perception of events, it can be difficult to know whether to tell the truth and risk distress, or whether to shield the patient from the truth and lie. In some instances, families see themselves as becoming devious as they learn how to prevent anxiety for both the patient and themselves by telling 'white lies'.

I have for my sins become devious, self preservational - I don't know. There are some things I know he will just get anxious about..... He said to me the other day "Have we done the tax return yet?" and I said "Yes" because it will be done, and it will be done by me and I will get him to sign it as and when necessary. So things like that partly to protect him and partly to protect myself. I manage things in a way that I never had to in the past. Something like a tax return for someone who used to be a chartered accountant, the idea that he can't do it I think that is where he really connects with what has happened to him. He doesn't need to be faced with that. [Interview E, Carer]

Usually the patient is unaware of this erosion of truth within the relationship. Any discomfort sits with the spouse or family members and becomes a question to settle within their own value systems.

Issues over truth telling may also arise as the family carer experiences the patient 'making things up'. However, more information about Alzheimer's and its impact can help create awareness and thereby reduce stress for the carer.

He also went through a session which was rather startling of making up stories..... I can't emphasize enough that it is important to talk to people who have had experience of what can happen, what it is like for other people because one of the Admiral Nurses pointed out to me, he is bright. When the brain is half way through a story I think she described it like this, and there seems to be an inconsistency then another part of his brain will possibly take over and say "Well of course that must have been" [Interview D, Carer]

Personal values need to be a guide for the spouse or family carer in making decisions around truth telling versus causing discomfort or stress. Making trade offs

between these can be difficult, but each spouse or family carer needs to find a balance that works for them. Greater ease is found with these dilemmas when the individual takes into account their own personal value system, the needs of the patient right now and consideration for the person they once were. Early planning and discussion around these challenges can help the spouse or family carer to set in place criteria for how these situations will be handled.

How to manage the safety of the person with Alzheimer's and others?

This issue again demonstrated the balance of two ethical goals, between the carer wishing to preserve patient autonomy whilst also recognising a duty of care to preserve patient safety. One of the fears that carers had was of patients not adjusting their behaviour to their lessened capability.

"He will do dangerous things like climb onto a flat roof and start repairing it in the snow and that sort of thing.That was a nightmare." [Interview D, Carer]

To handle this, carers tried to ask the patient to stop because it worried the carer, rather than suggest the patient was not capable.

The ability to drive a car was seen as significant, almost a symbol of independence in itself. Carers were conscious that maintaining patient mobility also gave them [the carer] some freedom as well. Therefore, mobility was highly valued, but only whilst safety was not compromised.

[On driving] "That is a big thing about independence but versus safety so that is a real big question. I want him to be as independent; he zips off to the gym and things and have some independence." [Interview A, Carer]

"We stopped driving then because at that stage I realised, I had seen a couple of things with driving where she had gone through a red light more than once. I had to say "You have got to think about other people." [Interview B, Carer]

The use of a mobile phone was an important factor in achieving safety and peace of mind. At the point at which the carer loses confidence in the patient's ability to use a phone, safety concerns triggered increased security.

"He has a mobile phone but he sometimes forgets how to use it...he won't know how to turn it on" [Interview C, Carer]

Where an external carer was available, their help could delay the transition from independence to 'safety-first'. However, this ended if the (spouse) carer lost confidence in the diligence of the external carer.

"[The external carer] lost her in the supermarket last week and I said....two things, you didn't take her phone which I insist that you take it because the chances are that she is

in the next aisle so if you phone it is not about her answering the phone, it is about you [external carer] can hear it ringing....." [Interview B, Carer]

There is evidence of Maslow's Hierarchy theory here, which places safety as a high priority need. However, the safety needs of others is also recognised by carers, demonstrating that combining needs across stakeholders is useful in making an informed decision for the good of society as well as the couple.

Future Planning

How to decide when to go into permanent care when there is a conflict between the person with Alzheimer's and family?

This issue proved to be one of the more difficult topics to discuss between carer and patient. Even if both parties want to talk about it, broaching the subject is stressful, in part due an inherent concern that one party may have quite different ideas and hopes for their care to the other.

"I hope, I wouldn't like to finish up in a Jewish Care Home particularly." [Interview E, Patient]

"I suppose I do keep a little bit ahead of him in that and in fact unknown to him I haven't yet told him this, but I did go and see someone from Jewish Care last week just to make sure that he is on the system so that as and when we do need some help it is there." [Interview E, Carer]

Another reason for avoiding discussion about future care is that one or other parties may find it saddening to think about.

"I feel I know where to get the information as and when I need it. I don't want to spend depressing time poring through it all. [Interview E, Carer]

Where discussion does happen, and conflict occurs, carers may choose to close down the conversation to avoid further upset, and yet have to go ahead with their own decision anyway, due to the practicalities of needing to act. Such behaviour can be very upsetting for carers, when they feel they are deceiving their partner.

"I suppose the topic of his future care because when I have brought it up, we talked about the finances of it, in my will I talked about sale of the house, a chunk of it being set aside for whatever care he may need. Of course I had to tell him that and he said "Why do you need to do that?" I said "Well we just don't know" and he said "I am doing fine." I said "Yes, you are" but then I go ahead and do it anyway, I have to. So that one we can't share and actually it is worse than that. We can't share what is happening to him because he doesn't really have the insight on how limited he has become. I think for the carer I think that is perhaps one of the biggest curses of Alzheimer's that you.....you face it alone." [Interview E, Carer]

Yet, couples that could achieve early discussion and agreement managed to avoid a crisis and even found that it helped find more innovative solutions, if only due to having more time available to search for them.

"I struggled with it, but because of that we sat down and we chatted about it, we hit it head on, we do most things in our lives and we hit it head on. We said "What are we going to do about it?" This is why we have worked hard to get this place [warden monitored accommodation]." [Interview F, Patient]

One of the benefits of such planning is that, in between arriving at the decision and acting upon it, the couple can feel they have genuine concordance – reached in a calm and mutually considered way, rather than in panic or crisis.

"It is because a lot of people don't do anything until they come to a crisis. For me once you come to it that is too late, they haven't actually asked that person what do they want, the person with Dementia." [Interview F, Carer]

For carers encountering a scenario of planning care arrangements in the face of conflicting views, it may be helpful to view such acts not as deceit but as a genuine search to plan 'the right path'. Deceit deliberately seeks to confuse the patient, whereas this is not the goal for care planning. It may be that the patient does not consistently show the conflict, and so an attempt to broach the topic in a range of settings may help achieve a more balanced assessment of different views.

How best to make decisions around end of life (quality of life versus longevity)?

For many couples, this topic is something either left unsaid or found very difficult to broach. In order to deal with this, participants described using practical issues such as legal planning as a way to 'break the ice'.

"We are trying to face up to these things, we have done the Lasting Power, we are trying to redraw the will, we really don't know..." [Interview A, Carer]

Another 'introductory' issue into the subject was financial matters and in particular how loved ones can be looked after.

"I don't know what to do really but I think we are trying to make it so that if this house, it will be left if one person needs care half the money has gone for their care but the other half the surviving person can live here and the money is ring fenced for the children in the long term. I think that is what we have tried to do." [Interview A, Carer]

However, in our own interview discussions, as in everyday life, patients and carers were then able to go on and describe deeper issues around end of life, such as a

patient's fear of carer mortality, and a recognition that they may no longer be 'growing old' at similar rates.

"It does worry me stiff to think that she could drop dead tomorrow, that kind of feeling that life doesn't go on forever and at some point she or I are going to die and the more that this goes on the more it hangs around. You can't ignore the possibilities."

[Interview D, Patient]

"Because you will get old, you won't get as old as quickly as I do." *[Interview A, Patient]*

Couples were very conscious that they face an uncertain future, where quality of life may be impacted. Thus, they did consider 'once-in-a-lifetime' activities, whilst they still had the time to enjoy them.

"I would have been happy once we got the insurance sorted out I said "If you want we will sell up and just go round the world for a few years" while you can. We have to be realistic about this, while we can and I would say to anyone I would have done that. If we had come back with no money I would have done it but because of her family, she felt that she wanted to still be near her family." *[Interview B, Carer]*

In the face of such uncertainty, some couples felt that making a real effort to get arrangements written down and "sorted out" provided a degree of satisfaction – that such difficult topics could be openly addressed and well handled as a result.

"What happens at the end of life, how I want the funeral done, where I want things donating, the brain donated to the Alzheimer's Society for the brain bio bank for research. Anything like that we are quite open. We are not only partners, we are good friends as well, we are best mates and can talk about anything." *[Interview F, Patient]*

"For us the future is quite simple really. We have sorted out all the things that we need to do that people refuse to talk about. We have sorted out things like end of life, funerals, what he wants towards his end of life." *[Interview F, Carer]*

Whilst 'once-in-a-lifetime' activities are at a grand scale, most couples considered that quality of life was best defined as (both) being able to continue to enjoy everyday activities they love, to a reasonable degree.

"I think basically we can laugh at death, dying. What we can't laugh at is method of or what they would do to us in between, you know that sort of thing. So I think every now and then you really do think more than twice about Dignitas and that sort of thing than you ever used to. So I feel we have just been taught a lesson really. But I think we are more positive than that, I think what we are saying is that we would like to go on enjoying the things we are enjoying." *[Interview D, Carer]*

Overall, patients and their carers found some success in framing their decisions in terms of being well organised, as perhaps any healthy, forward-thinking couple might do (wills, life insurance, organ donation). This approach made accessing the

topic easier than phrasing a question narrowly and bluntly (e.g. “What do I want to happen when I die?”). By discussing the topic at all, participants found they could both reflect on things that mattered to them across their whole lives (not just when in illness), as well as help define their personal ‘quality of life’ such as time with their family or maintaining a connection with their lifelong hobbies.

Recommendations for support in decision-making

Throughout this study, carers and patients described in great detail the kinds of everyday ethical issues they faced and how they tried to deal with them. In so doing, this alone demonstrated the richness of insight that is accessible – focused around the context of individual lives and relationships, rather than clinical outcomes.

Even from within a limited sample size, we recorded many accounts of similar issues, tackled in different ways. The consistent themes that were drawn from such accounts give us confidence in our findings and recommendations, in particular in relation to three transitional themes, which collectively offer a broad framework for decision-making to support patients and their families. In creating greater awareness and recognition of the three key findings, support can be offered to patients and their families in how to navigate a complex array of conflicts and dilemmas likely to be faced as the disease progresses. Specifically, the findings support the need to create greater awareness and recognition of:

1. *The inevitable shift to the spouse or family carer.* From everyday tasks, chores and decisions through to major decisions around finances, medical treatment and care, the spouse or family carer will need to gradually step in and take on a greater role within the partnership. This is an inevitable shift

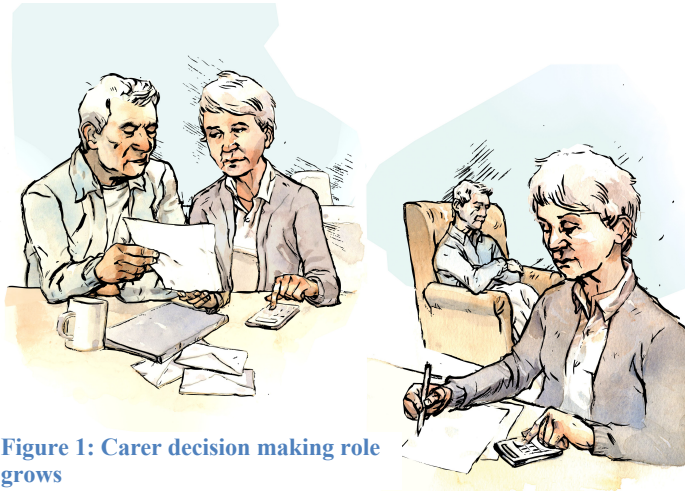


Figure 1: Carer decision making role grows

and one that may require the carer to develop new skills for example; driving, handling finances, shopping and cooking through to handling home help or using a Power of Attorney. However, early awareness that it will happen helps prepare and equip the carer and the patient for what lies ahead. Building a small network of trusted advisors can help provide support during this transition. Continuity in this group of people enables trusted advisors to spot changes that the spouse or family carer might miss. Everyday changes can be small and incremental and so overlooked by the spouse or family carer, whereas an objective observer may notice the shifts more easily.

2. *The concept of 'original' self and 'changed' self.* For carers and, in earlier stages of the disease, patients too, there was recognition of an 'original' self and a 'changed' self. By original self, we refer to the character and demeanor of the patient before disease onset. Carers typically wished to preserve the 'essence' or at least their memory of the original persona whilst also reconciling the need to adapt to a relationship with the changed persona. When taking on the responsibility of additional decision-making, a more inclusive and balanced approach is reached when the carer is able to hold both personas in his or her mind. This enables decision-making to respect the past, or 'the person he or she was' as well as acknowledge current needs. Early conversations to clarify values between the patient and carer can enable the carer to apply these when facing difficult choices further down the line. It is important to both parties to keep the spirit of the 'original' self present while respecting the needs of the 'changed' self at the same time. We recognise that this respect for an earlier, healthy 'self' relates to the 'externalist model'⁴ - i.e. of seeing Alzheimer's disease as external to the patient. We found evidence of patients and carers not wanting the disease itself to come to represent the patient in total. However, the traditional externalist model holds that, to be true to a patient's wishes, one must try to identify their views and beliefs before illness (e.g. the concept behind the living will). Our findings suggest that recognition of both 'self's' provides both a practical reflection of the current, whilst respecting the past. The goal is not to revert or return to the past (a futile act in any case) but rather to gain the best for the foreseeable future from 'what was' and 'what is'. In making our recommendation, we also considered the 'Constitutive Model'⁵ - that there is no original or changed self but that they have become one and the same. Yet, our findings were that carers and patients overwhelmingly preferred to carry some original self activities & memories with them for as long as possible, finding the 'death' of the original self as destructive and negative, if perhaps ultimately inevitable.

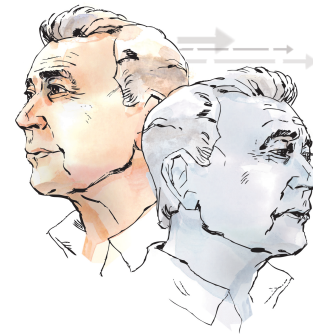


Figure 2: Respecting past and present 'self'

⁴ Ethical Foundations of Palliative Care for Alzheimer Disease, 2010 pp171-172

⁵ Ethical Foundations of Palliative Care for Alzheimer Disease, 2010 pp173-174

3. Decision making for two. It is obvious that Alzheimer's disease affects a change in the needs – physical, emotional and aesthetic – of the patient. Yet it is clear that carers' own needs also shift as the relationship adjusts to the situation. To be sustainable in the long-term, both need sets must be combined. Carers may feel guilt or a sense of duty when reviewing their own needs in a new future. Yet, a successful relationship includes a carer's own ability to cope with and maintain their quality of life. The concept of *Maslow's needs hierarchy* provides further structure in helping to make trade offs between difficult conflicts such as safety and freedom. This premise of a carer

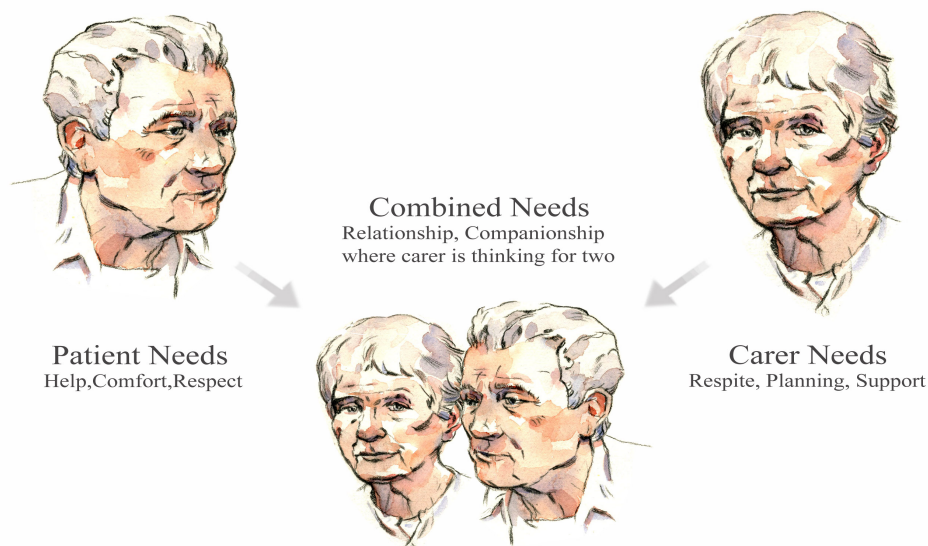


Figure 3: Decision Making for Two

taking on a responsibility for *combining needs* and making judgements for both parties' benefit defines an informed decision more broadly than solely determined by the requirements of the patient. Instead, it places Alzheimer's disease in a social context, and in particular in a relationship context. Just as the patient was part of a relationship with the carer spouse before the illness, so they are still defined as a person in a relationship with Alzheimer's disease. Success for the relationship and couple remains a partnership of needs. But the responsibility for managing those requirements has shifted towards the carer, and so the 'combined needs' set will need to adjust accordingly.

Scope of recommendation

It should be noted that our study scope has its limitations, which may impact upon the scale of applicability to a wider population. First, our patient

participants were limited to those in the relatively early stages of their disease. This was in part driven by the inclusion criteria of being able to consent and communicate verbally. In addition, the recruitment of patients with the assistance of Dementia UK may have introduced a selection bias towards those more actively and openly involved with describing their condition than a more randomly recruited sample.

Application

In terms of applying this framework, we see potential for training activities for people in roles such as nurses, carers and social workers, where these three transitional themes can help develop interviewing skills. We feel this could significantly drive greater awareness and more balanced decision-making for combining both patient and family carer needs.

We also feel that such a training programme could use many of the stories and accounts uncovered in this study as the basis for everyday training scenarios.

In seeking to develop such an application, we would recommend consultation and research with professional carers, who may be familiar with some of these issues, and can bring another perspective to how transition develops for patient, family carer and their relationship.

In presenting the findings of this study, we are conscious of including far more participant narrative examples than is commonly found in journal articles. We feel this is important for two reasons; first that the context of patients' individual lives is key to a full understanding of how decisions are reached, and by implication, that a process of editing patient experiences to a single sentence may lose the richness of detail that the methodology was specifically seeking to uncover. Second, we found great insight in paired accounts, where patient and carer often described the same event, but from their own, often-different perspective. By presenting such paired accounts alongside each other in this article, we hope that both views can be better appreciated, in order to support a more balanced decision-making framework to emerge.

Acknowledgements:

This study was sponsored by Pfizer Limited, and supported by Dementia UK.

We are very grateful to the patients and carers who consented to take part in the study, and describe so openly their experiences of living with Alzheimer's disease and the everyday challenges that it brings.

We would also like to thank the National Research Ethics Service for the advice and support provided in designing this study.