How Do People With Dementia Make Sense of Their Medications? An Interpretative Phenomenological Analysis Study

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Abstract

BACKGROUND: Managing medication is complex and multifaceted for people with dementia and their family carers. Despite efforts to support medication management, medication errors and medication-related hospital admissions still occur. This study investigated how people with dementia viewed and talked about their medications and medication-taking.

METHODS: An interpretative phenomenological approach (IPA) qualitative research design combining photo elicitation and in-depth interviews was used. People with a diagnosis of mild or moderate dementia confirmed with Montreal Cognitive Assessment, took photographs of anything they viewed to be related to medication, with/out the help of family carers, over any two-day period. The photographs were then used as cues for a subsequent in-depth interview. Interview data were analysed using IPA.

RESULTS: Twelve people with dementia were interviewed. In-depth analysis of interviews generated four themes: 1) Medication as a lifeline, 2) Overcoming the uncertainty about the effectiveness of donepezil, 3) Managing medications dominate daily lives and plans and 4) Sense of being and being in control. People with dementia view donepezil as a lifeline but some continually struggle to know whether it helps their condition. Despite this uncertainty, people with dementia continue to take their medications. Managing medications dominates their daily lives and plans and redefines them.

CONCLUSIONS: This study provided unique insights into how people with dementia make sense of their medication. Healthcare professionals can use these insights to shape their practice around medication prescribing and advice. The findings are also useful to researchers looking to develop interventions to support medication management within the home setting.

Background

Dementia is a major global challenge. Worldwide, 46.8 million people live with dementia and this figure is projected to increase to 74.7 million and cost $2 trillion per annum by 2030\(^1\). In the UK, the prevalence of dementia is estimated to double from 850,000 to 1.6 million people and cost £94.1bn per annum by 2040\(^2\). The impact of dementia extends beyond economics and includes the health, social and emotional lives of individuals, their families and wider society\(^3\)\(^-\)\(^5\). More than 90% of people with dementia live with at least one other health condition\(^6\) and with no cure for dementia on the horizon, medication plays a central role in managing the symptoms of dementia\(^7\) and the treatment of other existing co-morbidities.

Around 61% of people with dementia live at home\(^2\) where medication is a part of daily living. As a result, people with dementia and family carers have developed their own strategies for managing medication\(^8\)\(^-\)\(^11\). There are also interventions to improve medication management\(^12\), primarily rationalising the prescribing of antipsychotic medication. Managing medication, however, remains complex and multifaceted for people with dementia and family carers\(^10\)\(^,\)\(^11\) and can lead to medication errors and medication-related hospital admissions\(^13\). Figures show adherence rates in this group range from 17-
100\%. What is more, people with dementia are three times more likely to be hospitalised due to medication misadventure\(^1\) and when discharged, they have a 2-3 fold increased risk of taking either 30% less or 20% more of their prescribed medication\(^1\). Arguably, empowering this patient group to better manage medication at home should be a priority for health practitioners.

To provide help that is useful to them, it is first important to understand how people with dementia make sense of their medication, which in turn influences how they manage their medications within the home setting. Although there have been studies exploring how people with dementia talk about their diagnosis and how they make sense of it\(^1\), there is a dearth of literature focusing on how people make sense of their medications within the context of a dementia diagnosis. Personal accounts of experiences provide an important perspective; they not only give people a voice but also provide an important perspective to inform the development of support structures to enable people with dementia live well with medications. The aim of this study was to describe in-depth, how people with dementia view and talk about their medications and medication-taking.

**Methods**

2.1 Study design

An Interpretative Phenomenological Analysis (IPA)\(^1\) qualitative research design combining photo elicitation\(^1\) and in-depth interviews was used. Interview transcripts were analysed to explore how people with dementia ascribe meaning to medications and their use of it. The epistemological stance of IPA is that it is possible to gain insight into an individual's cognitive inner world. A researcher using IPA does this through a thorough and systematic interpretation of the dataset, paying close attention to each person's unique detailed accounts\(^1\).

2.2 Participant selection

Participants on the Berkshire Healthcare NHS Foundation Trust Research Interested List that met the inclusion criteria (see Box 1) were invited to participate in the study. Determining a sample size *a priori* for this study that focused on lived experiences was not straightforward\(^2\). When deciding on sample size, the principle of data saturation was used\(^3\). To meet the study aims, fifteen people with dementia were anticipated to be enough to generate rich and meaningful analysis. Trained researchers at the Berkshire Memory and Cognition Research Centre (BMCRC) identified, recruited and consented participants.

2.3 Setting

An experienced female qualitative researcher with a background in anthropology and health research (TS) conducted face-to-face interviews at the participant's home at a mutually suitable time.
Box 1: Study inclusion criteria

- diagnosed with Alzheimer’s Disease or mixed dementia with an Alzheimer’s Disease component
- Montreal-Cognitive Assessment (MoCA) score of 9 or above. (The scores include people with Alzheimer’s with mild to moderate cognitive impairment identified from the Research Interested List and confirmed with a cognitive assessment (MoCA) conducted by trained researchers.)
- prescribed at least one regular medication
- live in their own home
- receive some form of help with their medication from one or more family carer(s)
- capacity to consent (based on assessment by trained researchers).

2.4 Data collection

Participants were co-creators of research knowledge; they were loaned a digital camera and asked to take photographs of anything (for example objects and places not limited to their own home) that they viewed to be related to medication and medication-taking, over any two-day period. Verbal and written guidance were provided. The photographs were then used as cues for a subsequent in-depth interview – see Box 2 for the interview topic guide. Interviews were digitally audio-recorded and transcribed verbatim. To ensure participants were comfortable, some interviews took place with their carer present forming participant-carer dyads.

Box 2: Interview Topic Guide

Warm up questions

- How did you find using the camera?
- How did you find the process of taking pictures? Were they planned or spontaneous?

Main questions

- Present participant with one picture at a time, and use every picture taken: Can you tell me what this picture means to you? Were you thinking of anything specific when you took the picture?
- General: What place does medication have in your life at this moment? Have you changed the ways you use medication over time? How has medication affected your relationship with others?

Closing

Is there anything else you want to tell me or add anything to what you have already said?
2.5 Data analysis

Analysis involved familiarization with each interview transcript in conjunction with the original audio recordings, making notes on specific aspects of the transcript (descriptive, linguistic and conceptual), interpreting and then classifying these notes to develop initial themes (similar clusters of ideas) and subsequently a master list of themes and subthemes to capture the essence of the participant’s account. This process was repeated for every transcript on MS Microsoft Word. A comparison of all the themes and sub-themes for each transcript was made and recurrent patterns across all transcripts identified and consolidated into a list of super-ordinate themes that accounted for the experiences of the sample. The researchers had no prior relationship with any of the participants. Throughout the analytical process, the researchers’ ‘bracketed’ their own assumptions, experiences and judgement and kept reflexive notes. Two researchers (TS and RL) independently analysed the entire dataset. RL is a trained qualitative researcher and an academic pharmacist. TS and RL discussed their analyses to arrive at the themes presented in this paper.

Results

3.1 Participants

Interviews took place between January-May 2017. Twelve in-depth face-to-face interviews were conducted with people with dementia. Table 1 shows the participant characteristics.

58.3% (n=7) of the participants were male with a mean age of 75.2 years (standard deviation (SD) 9.1, range 60-89). Most participants had received a diagnosis within the previous 5 years (n=10, 83.3%). The mean MoCA score was 17.3 (SD 4.4, range 12-25). Two participants lived on their own. Interviews with participants lasted between 18 and 66 minutes (mean 35 minutes).

| Table 1: Demographic details of participants (n=12) |
### 3.2 Interview findings

In-depth analysis of interviews using IPA generated four main themes: 1) Medication as a lifeline, 2) Overcoming the uncertainty about the effectiveness of donepezil, 3) Managing medications dominate daily lives and plans and 4) Sense of being and being in control. Figure 1 shows the relationship between the four inter-related themes.

**Theme 1: Medication as a lifeline:** "Without it [medication], life would be very difficult or impossible"
Participants talked about their experiences from a position of acceptance of their dementia diagnosis and their need for medication.

“I know that I wouldn’t be probably as I am without the medicine I take on a daily basis. It’s not a choice thing. It’s a necessity of life I guess, for me. So, I’ve accepted that and that’s it.” Participant 9

As such, medication, specifically donepezil, was viewed as the primary help to manage dementia. Donepezil was not a cure, but key in halting the deterioration of dementia. All knew that donepezil was to be taken for life because there is currently no cure. One participant made explicit her own diagnosis of dementia as a terminal condition. She talked about donepezil as part of palliative care.

“Well until they can give you new brain cells, that’s it really. All they can do is palliative, isn’t it really?” Participant 10

Donepezil was a lifeline and hope for ‘more years’ with their loved ones. Participants wanted to enjoy life with their family and donepezil was a key part to enabling life to continue.

“In one sense. It is one of the key things in my life. Without it life would be very difficult or impossible wouldn’t it? Yes. Oh yes, I regard it as a very necessary and important thing that I must be careful with, that I must keep on taking it and taking it at the right time, yes.” Participant 11

To not take donepezil was to give up on life. Participants wanted to live life to the fullest, for as long as possible and donepezil was a means for that to happen.

“I take it [donepezil] because I know it helps me. So, I’m, there’s no point me saying I don’t want it, I, then I may as well give up... But that helps me to keep going and enjoying life and that’s what, that’s what I want to do.” Participant 8

**Theme 2: Contending with the uncertainty about the effectiveness of donepezil.**

Although participants did not view donepezil as a cure for dementia, they expected it to have an effect on their dementia; positive or negative. When talking about these effects, however, there was a tentative response.

“I’m grateful that these things have been developed because I know that they have **probably prolonged my memory**, if I were without them, I would be pretty helpless I think.” Participant 12 [emphasis added]

“I guess I think I’ve lived a bit longer maybe, taking all this medicine. **I’m not sure**.” Participant 9 [emphasis added]

The participants’ view about the effectiveness of donepezil were tentative because they saw no changes in cognitive test results, could not perceive relief of their physical symptoms or did not associate a positive emotional response from taking it. Contrast was made with taking other medications such as
aspirin for a headache or lansoprazole for stomach pains; here, the removal of pain would indicate that the medication had taken effect but not so for donepezil.

“It’s [picture of Venice], reminds me of holidays and relaxation which the tablets [donepezil] were supposed to give me same pleasure, make me feel better but they don’t.” Participant 5

Despite the uncertain and imperceptible effects of donepezil, participants were determined to continue taking it; the risk of a deteriorating condition was too great.

Theme 3: Medications dominate life

It followed that medication dominated the daily lives and plans of participants. Medication-taking revolved around the establishment and maintenance of an intricate personalised routine within the home. The extent and complexity of the routine differed. Routines were associated with a particular time, space, activity and specific objects. For example, medication in a visible pillbox on the kitchen table was taken at breakfast time. A wide range of objects were used such as compliance aids, alarms, calendars, and record books – these were made clearly visible and easily accessible. These routines were established over time following trial and error (see Box 1). Participant-carer dyads were strict in following these routines.
An established routine was key in helping participants take their medication as independently as possible. Social events and holidays however, required further proactive planning with medication-taking. For one participant who takes a motorcaravan on holiday, the inside of the motorcaravan was set up to be almost identical to their kitchen at home to recreate a familiar environment associated with medication-taking. One participant poignantly talked about his experience of restricting himself from drinking wine during “card night” with his family because he is on medication (see Figure 2).

“Right this picture, it’s obviously, someone has had a glass of wine, there’s some crisps there...It probably meant that if we were drinking wine I shouldn’t drink too much of it because I need to take the tablets.”
Participant 5

**Theme 4: Sense of being and being in control**

Participants showed insight when they talked about themselves as someone with a diagnosis of dementia. There was a strong sense of ‘being”; they talked about being grateful for being alive and for their life.

“Yeah, another day outside with the sun shining out there, thinking I’m lucky to be alive..” Participant 5
There was clear acknowledgement across all participants that they needed others to journey with them, living with dementia. Several showed empathy towards their carer.

“I mean it must be irritating at times when you’ve told me something and then you, half an hour later or perhaps an hour or two later you will say, well I told you that, and I’ll say oh yes, sorry, yes, of course you did.” Participant 12

“Participant: When you hear that large thumping noise in the bath which does not happen very often, but that’s me falling over.

Carer: Oh well. But anyway, we can mention it to the doctor when we go next, we have already.

Participant: Well you’ve put up with a lot haven’t you?” Participant 7

The relationship between the participant and carer was crucial in determining the participant’s sense of self. Most participants had carers who were empathic, encouraging, patient and kind. These carers played a key role in ‘scaffolding’ the participant to enable them to be as independent as possible in managing medications. They ‘engineered’ the environment with and for the participant to take their medications. This resulted in participants being able to manage their own medications as independently as possible within a (carer-) controlled environment. Their ability to manage their own medications i.e. being in control, was key to their sense and view of self, and their wellbeing. Being in control of their medications meant being in control of their dementia.

“There it is. Well that’s it. I think it’s absolutely brilliant and you can see what it’s called. PPPP, and I just think it’s great that I can tick everything off so easily, yeah, and yeah, it’s made all the difference, because I’d never have remembered otherwise, would I?” Participant 2

“Oh I’m quite pleased with that really. I’m not, I don’t know, maybe I’m doing myself down a bit but I’ve always thought I’m not the most organised person in the world. But with this, I’m organised so that’s comforting.” Participant 10

Managing medications can also cause stress and tension within the participant-carer dyads and this was often due to differing concerns and priorities. Where the relationship between participant-carer dyads were fraught, these related to past negative experiences for example, the participant took an accidental overdose. In these cases, carers took over all or most of the medication management process, for fear of potential harm to and loss of the participant. The need to manage medications led to a change in dynamics within the participant-carer dyad and as a result, some participants viewed and talked about themselves differently, both positively and negatively.

Participant: Do you think I’m a simpleton? [angry voice]

Carer: Course I don’t think you’re a simpleton. I know you act like one but

Participant: I know. I take five in the morning and two at night. Is that correct?
Carer: No. But that's all right.

Participant: Right so what do I take then? Participant 9

Most participants were careful to only take medications prescribed by the doctor. But for one participant, the carer researched a combination of medication/vitamins that could help dementia and made the participant take them, which the participant agreed to, against the consultant doctor’s advice.

“I researched, in America, to do with dementia a dose, small dose of folic acid, B6 and B12 daily helps, there’s been a small research, they’ve done quite a few small studies, they haven’t done big studies... and I put you on that, and Dr (name), your doctor, she didn’t want us to go on that, she said, no don’t do that... But I wasn't interested in that, I wanted as many good things going in..[for the participant to take it].”

Participant 4 [emphasis added]

Discussion

This study provided unique insights into the views of people with dementia about their medication. Our principal findings were that people with dementia viewed medication, specifically donepezil, as a lifeline but had to continually contend with the imperceptible effects of the medication on their condition. Despite the uncertainty, people with dementia continue to take medications and the management of medications dominates their daily lives and plans and comes to redefine them.

Being diagnosed with dementia is a life-changing event. Although non-pharmacological interventions are available to promote cognition, independence and wellbeing, people with dementia viewed donepezil as the cornerstone for managing their condition, reflecting a biomedical view of health. People with dementia were aware that their condition was incurable. Some described their condition as terminal and their current treatment, palliative. Despite this, donepezil was viewed as a lifeline to help with dementia symptoms. The participants would take their medication religiously. A few people with dementia however, questioned whether it was ‘worth’ continuing to take donepezil because they could not be sure whether it was effective in managing dementia symptoms. This apparent lack of efficacy is unsettling and problematic. But, due to there being no cure for dementia, participants viewed the risk of deterioration to be greater than the burden and issues related to managing medications. Thus, they too continued to take donepezil. These findings were consistent with Hutchings et al.’s study reporting varied experiences of people with dementia taking cholinesterase inhibitors. Most of the people we interviewed had comorbidities, with both symptomatic and asymptomatic conditions, and some viewed and described donepezil as being more important than medications prescribed for other conditions. Our findings aligned with Lindstorm et al.’s study where people with dementia and carers expressed relatively high hopes for medications used to help with memory loss. Our findings however, contrasted with Rathbone’s work (2020) where patients with asymptomatic and symptomatic conditions shared similar experiences of taking medication. Views from people with dementia in this study also contrasted with those of people
with other terminal illnesses who are reported to undergo a ‘transition’ period during which they place less importance on certain types of medication\textsuperscript{26}.

The place that medications have in the lives of people with dementia and their family carers was reflected in the way medication dominated their lives. There is increasing understanding of how people with dementia manage their medications\textsuperscript{10-11} highlighting the complexity and all-consuming nature of the task. This current study, however, has broadened our understanding of the drivers that lead people with dementia and family carers to persevere with the medications through the development of a range of intricate, personalised routines. The ‘success’ of each routine was usually heavily dependent on the family carer, consistent with previous studies\textsuperscript{9, 27, 28}. A change in the dynamics of the dyadic relationship occurs because of the need to manage medications and comes to redefine how the person with dementia views themselves, whether positive or negative. The reciprocal dyadic relationship between the carer-participant was vital in establishing “sense of self” among the participants, consistent with Tuomola \textit{et al.}’s work\textsuperscript{29}.

4.1 Implications for practice and future research

Understanding how people with dementia view medications is key in shaping conversations around treatment options. Healthcare professionals can, and arguably ought to, proactively seek the perspectives of people with dementia, to explore their assumptions and expectations about medications during consultations. How people with dementia and family carers view medications can influence not so much whether and how they take the medications but how they understand the impact of the medication and therefore potentially their wellbeing. Communication around monitoring and frequency of monitoring of dementia symptoms is key to alleviate doubts and worry and to ensure medications are taken safely.

There appears to be few theory-driven interventions specifically designed to support people with dementia and family carers manage medications within the home setting. Interventions such as reducing psychotropic drug use\textsuperscript{12} and bespoke strategies developed by family carers and people with dementia\textsuperscript{11} exist. But these have been piecemeal focusing on specific and often limited aspects of medication management. There is then arguably a place for theory-driven interventions to support people with dementia and family carers manage medications daily with their homes. The findings of this study could therefore be used to inform the development of formal interventions to be tested in future studies.

Strengths And Limitations

There is limited in-depth exploration of the lived experiences of people with dementia and specifically their views on medications. Our original study adds to this body of knowledge through careful and sensitive elicitation of knowledge, co-produced with people with dementia. The use of pictures, taken by people with dementia, had a two-fold advantage. First, giving control to people with dementia to ‘set the agenda’ of the interview and secondly as cues to trigger their memory when sharing their lived experiences. Photo elicitation is not new in dementia research but not often used in the context of
medication management. The methodological approach could be of relevance to researchers in countries across the world in eliciting culturally specific lived experiences. Participants were homogeneous in terms of ethnicity; they were all white. Participants from different ethnic and cultural backgrounds may have different views of medication.

Conclusion

This study provided unique insights into the views of people with dementia’s in terms of their medication. Dementia medication, donepezil, was viewed as a lifeline despite its imperceptible effects. Healthcare professionals can use these insights to shape their current practice around medication prescribing and advice. Future work can focus on using these insights to inform intervention development work to support medication management within the home setting.

Declarations

Ethical approval and consent to participate

The study received ethical approvals from the United Kingdom National Health Service Health Research Authority (IRAS ID 200310), the English South East Coast – Surrey Research Ethics Committee (reference: 16/LO/1574) and the University of Reading Research Ethics Committees (reference: 16/57). The study was conducted in accordance with the relevant ethical guidelines as set out by the ethics committees. All participants provided written informed consent prior to participation in the study. Participants were informed prior to and during the consent-taking process that their participation was voluntary and that they were free to withdraw from the study should they wish to without prejudice.

Consent for publication

All participants provided written consent for photographs taken as part of the study, and anonymised portions of transcripts, to be used in publications.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors’ contributions

RL conceived the study. RL and PD secured funding for the study. RL, TS and PD contributed to the study design. TS conducted the interviews. TS and RL analysed the study data. RL drafted the article. TS and PD revised the manuscript critically for intellectual content. All authors agreed and approved the final manuscript.

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Figure 1

Relationship matrix of super-ordinate themes

**Medication as a lifeline**
- Acceptance of medications: “I’ve accepted that and that’s it”, “It’s not a choice thing”
- Need for medication: “It’s a necessity of life”, “without it, life would be very difficult”

**Contending with the uncertainty of the effectiveness of donepezil**
- Expectation and ambiguity: “probably prolonged my memory”, “without them I would be helpless”
- Lack of perceivable effect: “You don’t feel it”, “it supposed to make me feel better, but they don’t”

**Sense of being & being in control**
- Being: “Lucky to be alive”
- Need for others; key role of carers:
- Being in control of medication meant being in control of dementia

**Medication dominates life**
- Intricate personalized routines: associate with time, space, activity, objects
- Proactive planning: “we need to find a place in the motorcaravan to take tablets”, self-restriction at social events
Figure 2

A picture taken by Participant 5 when asked to capture views about medication and medication-taking.