Research Square

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How do doctors discuss dementia treatments with patients? Content analysis of the presentation of treatment information, benefits and side effects

Sarah Jane Smith
s.j.smith@leedsbeckett.ac.uk

Leeds Beckett University
Alys Wyn Griffiths
University of Sheffield
Peter Knapp
University of York
Rebecca Dickinson
University of Leeds
Jemima Dooley
University of Exeter
Gregor Russell
Bradford District Care NHS Foundation Trust
Rachael Kelley
Leeds Beckett University

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Abstract

Background

The benefits and side effects of pharmacological treatments for dementia are inherently difficult to qualify. Little is known about how they are discussed with patients and relatives in consultations, despite this having an impact on shared decision making, understanding of medications, and adherence. This study sought to understand how the benefits and side effects of treatments are communicated in clinical encounters.

Methods

29 memory assessment clinic consultations across two UK NHS Trusts were video recorded, involving a total of ten doctors, 29 patients and 32 relatives or supporters. The consultations were analysed using content analysis to identify patterns in communication.

Results

The findings indicted that whilst there were some common approaches to describing medications –approaches varied in ways that could influence understanding and decision-making. Benefits were most frequently presented as symptom management designed to improve symptoms, focused on memory and cognition. Discussions of risk/benefit, prognosis and shared decision making were not present in all consultations.

Conclusions

Examining the findings in the context of best practice and guidance there are clear recommendations. Our data showed positive framing of the benefits of dementia treatments by clinicians. There was also a lack of consistency in the way that both benefits and side effects could be described. Recommendations include guidance for discussing dementia medications in ways that promote shared decision making including 1) caution about the use of leading language 2) ensuring consistent and transparent communication of benefits using education and training for clinical staff or patient decision aids where appropriate.

Background

Effective communication of the risks and benefits of medications is a priority in the field of medicine and psychiatry[1] and warrants particular attention in dementia care because of the additional complications that cognitive impairment creates for communication and decision making. In the UK, assessment and diagnosis typically occurs in specialist Memory assessment services (MAS). For eligible patients (i.e. with a diagnosis typically of Alzheimer's type dementia or mixed dementia), pharmacological treatments in the UK (as of 2025) take the form of four approved medications: donepezil, rivastigmine, galantamine (cholinesterase inhibitors), and memantine[2]. Lecanemab (a human monoclonal antibody drug) has been licensed for use in the UK by the Medicines and Healthcare products Regulatory Agency (MHRA), but has not been recommended for use in the NHS at this time due to the benefits being judged to be too small to justify the costs and the severity of and intensive monitoring required for side-effects[3]. Pharmacological treatment for dementia is challenging as the treatments are not curative and it is difficult to predict who will benefit because of individual variation in progression of the condition. Donepezil, the first line treatment, has been shown in clinical trials (and practice) to have limited side effects (most commonly mild to moderate gastrointestinal side effects), and has modest benefits in terms of symptom management [4].

Effective treatment communication has moved on from paternalistic medical models in which physicians make decisions on behalf of patients and supply information, towards models of shared decision-making (SDM). Shared decision-making is mandated by the NHS[5] and GMC[6] in the UK and requires that treatment initiation is collaborative; based on evidence-based medicine and clinical expertise as well as what matters most to patients. Shared decision making incorporates three elements: recognising and acknowledging that a decision is required; knowing and understanding the best available evidence (including the risk and benefits); and incorporating the patient's values and preferences into the decision [7]. It has elsewhere been described as 'an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences'[8]. The benefits of SDM can include raising compliance with agreed treatment, improving patient safety, reducing health inequalities and curbing overprescribing.

Dooley and colleagues[9] have previously investigated shared decision making in MAS, examining initial mentions of medication to explore how doctors involve patients with dementia in decisions to start medication, including how this affects acceptance of medication. In most initial mentions they identified an assertion from the clinician about medication i.e. "there is 'some medication' to help memory loss" followed by a recommendation relating to the medication. They found that patient responses often did not clearly indicate agreement; 63% passively resisted medication by responding minimally (e.g. 'mhm'), 18.5% actively resisted medication ('Is it going to help, I take medication already?'), and only 18.5% explicitly accepted medication ('Yes I'll take them'). Of further note, medication was just as often prescribed when patients resisted as when they accepted the proposal to take it. These findings suggest that shared decision may be limited in MAS. The current study extends this research by examining how information is provided beyond the initial recommendation (i.e. benefit/risk communication) and how this might inform the decision-making process.

The European Medicines Agency (EMA)[10] have identified the need to improve risk and benefit communication to support informed decision-making. Aiding decision making requires information concerning the risks, benefits and consequences of healthcare options to be clear and understandable. This

necessitates that 1) physicians are informed about the benefits and risks of available treatments and 2) the risks and benefits are communicated effectively. In psychiatry, as well as other fields of medical communication, we know that risk benefit communication can be suboptimal because it fails to meet one, or both, of these requirements. Research raises questions about the ability of physicians to adequately understand risk benefit profiles and communicate these effectively[11].

Accurate information about the outcomes of taking medication for dementia is further complicated because the effectiveness is difficult to qualify. Clinical trials of treatment effectiveness have typically relied on improvements being represented by quantifiable score change, for example a systematic review of donepezil identified that the Alzheimer's Disease Assessment Scale is commonly used as a key outcome[4]. However, in practice, objective improvement on cognitive scores does not neatly correspond to symptomatic change. Similarly, predicting which patients will benefit from these treatments, and by how much, is difficult to determine[12].

In summary, evidence to date indicates that people living with dementia may not be optimally involved in decision about medication. It is important we understand how medications are being presented to ensure effective communication of their risks and benefits and facilitate involvement in the decision-making process. This is even more important given the new medications that are being made available for dementia, with different risk/benefit profiles to those that are currently available. This qualitative study, conducted as part of a wider study[13] into communication of pharmacological treatments for dementia in MAS, sought to explore, using content analysis, how the benefits and side effects of dementia medications are discussed in clinical appointments, with the aim of developing recommendations for current and future practice.

Methods

Design

This study was qualitative and used focused video ethnography (see [14] for use in health research) utilising transcripts of video and audio observations of clinical appointments in MAS, which were analysed using content analysis. The two MASs were based in two NHS Trusts in the North of England. The MASs served a combination of inner city and rural areas, and cities with ethnically diverse populations.

Participants

People attending MAS and receiving a diagnosis of dementia for which a pharmacological treatment could be offered, their relative(s)/supporter(s) who attended with them, and medical clinicians (e.g. psychiatrists, consultants, specialty registrars, specialist doctors) working in the MAS.

Clinicians

Clinicians within each MAS were approached via a lead clinician and invited to take part in the study. They were consented by a researcher ahead of potential observations being scheduled. Overall, ten clinicians took part contributing 29 consultations overall. The clinicians who led each consultation are identified in the first column of Tables 2–4.

People with dementia and their family members/supporters

Each MAS identified all patients who had/would be offered a diagnostic appointment with a consenting clinician over a forthcoming time period, and these patients were screened by the clinician to target only those who were likely to have a pharmacological treatment offered to them if given a dementia diagnosis. People with dementia and their relative/supporter were initially approached by letter, followed up with a phone call from a member of staff from the NHS Trust. 29 people with dementia and 32 relatives or supporters took part.

[Table 1 here]

Table 1
– Patient and Relative/Supporter Demographics

	Patients	Relatives/Supporters
	N 29 (%)	**N 32 (%)**
Diagnosis		
Alzheimer's Disease	23 (83%)	
Mixed Dementia	3 (14%)	
Lewy Body Dementia	1 (3%)	
Age	**N = 18**	**N = 17**
30–39	-	2 (12%)
40–49	-	2 (12%)
50–59	-	5 (29%)
60–69	2 (11%)	6 (35%)
70–79	10 (55%)	1 (6%)
80–89	6 (33%)	1 (6%)
Gender	**N = 29**	**N = 32**
Female	21 (72%)	22 (68%)
Male	8 (28%)	10 (31%)
Ethnicity	N = 18	N = 19
White British	14 (78%	8 (79%)
White Welsh	1 (6%)	1 (5%)
White Scottish	1 (6%)	1 (5%)
White New Zealand	1 (6%)	-
Black Caribbean	1 (6%)	1 (5%)
Mixed Heritage	-	1 (5%)
Relationship		**N = 32**
Partner/Spouse		9 (28%)
Daughter		12 (38%)
Son		6 (19%)
Granddaughter		2 (6%)
Niece		1 (3%)
sister		1 (3%)

Ethical considerations

Ethical approval for the study was gained from the National Research Ethics Service panel [details **Yorkshire & The Humber - Bradford Leeds Research Ethics Committee** reference 21/YH/0032] on 8.3.21 and the study was conducted in accordance with the principles cited in the Declaration of Helsinki. All participants gave fully informed written consent prior to data collection. Where participants had dementia, an assessment of capacity to give informed consent was conducted in line with the Mental Capacity Act 2005.Where participants lacked capacity, advice about their wishes was provided by a personal consultee. Continued willingness to participate was checked at each subsequent data collection point along with mental capacity.

Data collection

As data collection occurred during the COVID-19 pandemic, a range of in person and remote methods were employed for the observations. MAS appointments took place remotely using video software or telephone, and in person in clinic settings located within NHS sites or during home visits. Appointments involved clinicians, the patient, and their relative/supporter(s). Appointments were audio or video recorded either via the video-calling software used for the appointment, a separate video-recording device set up in the same room, or via a dictaphone to record audio only, dependent on participant preference, practicability and COVID-19 restrictions at the time. Researchers were not present in the room during any of the appointments; video recording

equipment was set up and started by the researcher ahead of the appointment, with clinicians responsible for operating Dictaphones and recordings undertaken via video-calling software.

Public and patient involvement

A lived experience advisory group was established consisting of six people with personal experience of attending MAS for a dementia diagnosis; either their own diagnosis (n = 3) or the diagnosis of a relative (n = 3), residing across England. The group met six times during the project, via videoconferencing. Members contributed to and influenced the design, delivery and analysis of the study, for example by advising on content of interview topic guides, discussing recruitment and consent processes, reading and commenting on data excerpts to support analysis and contributing to dissemination plans and outputs.

Sample

In total there were 29 video/audio recordings. Only one observation took place between a clinician and a patient, and 28 between a clinician, patient and at least one relative. The participants in each consultation are described in Tables 2–4.

Data Analysis

A thematic content analysis approach was taken to analyse the discussions about medications following methodology cited in Krippendorf[15]. Prior to analysis, the extract from each video/audio recording of the consultation where medications were discussed was identified and transcribed. These made the sampling units for the study (i.e. one consultation = one sampling unit). The audio/video length of the sampling units from the consultation ranged from 4 mins 36 sec to 25 mins 50 seconds – average 11 minutes 5 seconds. The content analysis of the n = 29 sampling units from the consultation entailed a three-stage process, outlined below.

Stage 1

Four members of the research team, including one clinician (SS/GR/RD/JD) independently examined the same subset of the sampling units (consultations) (n = 10) to develop a codebook. First, each researcher open coded each transcript, by identifying units of the text within the transcript that could potentially represent meaningful information (coding units). Coding units refer to the portions of the text that represent something meaningful in terms of characterising how medications were being discussed. The coding units were discussed and agreed between the researchers to agree a consensus of categories – resulting in the final codebook. The codebook comprised three overarching categories (Benefit Statements, Side Effect Statements and Treatment plans). These codes were then applied to the textual analyses described in stage 2.

Stage 2

Three coders (SS, AG, PK) independently applied the codebook indexing to all 29 sampling units (consultations). As per the method suggested by Krippendorf (), because the sampling units tended to be large, and coding a larger portion of text can become unreliable, each sampling unit (consultation) was further dissected into context units (limiting the amount f information under consideration at any one time) for ease of coding. As recommended, the context units in our samples were defined by natural breaks in the flow of discussion or topic, rather than arbitrarily (e.g. after a certain number of sentences).

The number of context units in each sampling unit (consultation) depended on the length of the sampling unit and ranged from 4 to 12 units (average 6.9), an overview is presented in each of the results tables (2–4). The codebook instructed coders to read each context unit and identify first the explicit presence or absence of the categories, for example – a benefit statement. Should a benefit statement be present in the context unit the researchers indicated which subcategories and code(s) applied. An overview of the categories and example coding units is provided as supplementary data.

More than one code for per category could be applied per context unit. For example, if researchers identified that a benefit statement is present in the context unit, they would assign an appropriate code. e.g. indication that the treatment is not curative would be coded (under subcategory *Treatment Purpose*), which may also sit alongside an indication of delayed decline (under *magnitude of effect*) (see Fig. 1 for example process).

[Figure 1 here}

Stage 3

Once all coders had reviewed the 29 consultations, any disagreements in coding were managed by applying a formal decision rule-majority judgment. If at least two raters endorse the presence of a code within a context unit, it was reported. If there was no majority agreement the code was not endorsed and not reported. Thus, the final data presented (Tables 2–4) represents the majority agreed codes applied to each context unit / sampling unit.

Results

The results are presented by category. On average per consultation, 40% of the units of text considered in the consultation included benefit statements, 43% included side effect statements and 69% included treatment plan information. Thus on average more of the overall discussion in each consultation was given to the treatment plan than the benefits or side effects. Each of the categories are considered below in turn and provide the highlight findings regarding the

commonality of approaches to presenting the benefit, side effects and plans for treatment across the consultations. Tables 2–4 present the detail of these findings.

Benefit Statements

In this category the presence of any discussion of treatment benefits was considered, inkling treatment purpose, likelihood and magnitude of treatment effects. An overview of the codes indicated for benefit statements over the 29 consultations is provided in Table 2. Column three indicates the number of context units (sections of descriptive text) for each consultation that feature a benefit statement. The remainder of the table shows, for each consultation, whether the code featured at all in the discussion (ticked). The numbers next to the tick indicate how many times the given code was endorsed in the consultation.

Treatment purpose was most often described as being related to symptom management, with 26/29 consultations featuring this code. For example:

It helps with some of the symptoms with dementia, like memory issues.

The approach we found to be most common was clinicians referring to symptom improvement (20/29) as the *effect of the treatment*, targeting *symptoms* related to memory and cognition (22/29).

Less commonly, in around half (13/29) of the consultations, clinicians specified that the *treatment purpose* was not curative. With one third of consultations, at some point, suggesting that treatments may be disease modifying *"And it will slow the progression of the disease*.

Similarly, with regards to *treatment effects*, around half referred to symptom reduction or delay e.g. *"It's not a medical cure but it does help to some degree and we're hoping to at least stop things getting worse for a reasonable period of time"*.

Within the same consultation it was common for clinicians to adopt different approaches to describing benefits. For example, whilst most clinicians at some point describe the treatment as symptom management, within the same consultation additional treatment purposes or effects such as reducing symptoms, delaying symptoms or modifying the course of the disease, may be described. This is notable as it can make it difficult for the patients to discern the true nature of the benefits of the medications.

Most consultations featured similar codes for describing the likelihood effects, namely describing them as medium (21/29) "*for most people*" or definitive (19/29) e.g. "*you'll always be a little bit better off with the tablet than without*". There was less consensus across the consultations regarding magnitude of effect with around half of the consultations referring to small (13/29) or moderate (13/29) effects and 10/29 referring to large effects.

In terms of providing a qualifying statements about the benefits (descriptions of magnitude or likelihood) of the benefit, around two thirds (20/29) included verbal qualification. Only 3/29 included numerical qualification of benefit e.g. *"about sort of 70 per cent of people, it can have a positive impact."* All consultations, at some point, included benefit statements with no supporting evidence, and 11/29 included benefit statements with evidence pertaining to personal experience. Only 3/29 consultations featured reference to clinical trials as evidence.

Finally, In terms of personalisation of the benefit statements, nine of the consultations included statements that had explicit personalisation e.g. *"I wonder whether it might help with some of the anxiety that you've noticed, and that might have a positive impact for you*

Clinician	Patient	Benefit units/total units	Benefit statements								
			Treatment purpose					Treatment effects			
			Non Curative	Symptom management	Disease modifying	Unspecified statement of benefit	Not mentioned	Delay	Symptom Reduction	Symptom Improvement	Not men
1	1	4/7		✓ 2	✓ 1	✓ 1		✓ 1	✓ 1	✓ 2	
1	2	4/9		✓ 3	✓ 2			✓ 1		✓ 3	
1	3	3/7	✓ 1	✓ 1	✓ 1	✓ 1		✓ 1		✓ 1	✓ 2
2	4	3/6	✓ 1	✓ 2				✓ 1	✓ 2	✓ 1	✓ 1
2	5	3/6	✓ 1	✓ 2				✓ 1	✓ 1		✓ 1
2	6	2/6	✓ 2	✓ 1		✓ 1				✓ 1	✓ 1
3	7	1/6			✓ 1					✓ 1	
4	8	2/5	✓ 1	✓ 2				✓ 1	✓ 1	✓ 2	
4	9	3/11		✓ 3				✓ 1	✓ 2	✓ 1	
4	10	3/8	✓ 1	✓ 2	✓ 1			✓ 2	✓ 1	✓ 1	
4	11	2/8	✓ 1	✓ 1		✓ 1		✓ 1		✓ 2	
5	12	4/8		✓ 2			✓ 1		✓ 1		✓ 2
1	13	2/7	✓ 1	✓ 1		✓ 1	✓ 1	✓ 1	✓ 1		
6	14	4/12		✓ 3	✓ 1			✓ 3	✓ 1	✓ 1	
6	15	3/7		✓ 2	✓ 2			✓ 1		✓ 3	
6	16	2/8	✓ 1	✓ 1	✓ 1			✓ 2			
6	17	2/11	✓ 1	✓ 2					✓ 2		
6	18	2/7	✓ 1	✓ 1					✓ 2		
7	19	3/7		✓ 2	✓ 1					✓ 3	
7	**20**	2/4		✓ 1		✓ 2				✓ 2	
8	21	1/7					✓ 1				✓ 4
7	22	3/7	✓ 1	✓ 2					✓ 1	✓ 2	✓ 1
6	23	1/6	✓ 1	✓ 1					✓ 1		
7	24	3/4		✓ 2						✓ 2	✓ 1
9	25	3/5		✓ 2	✓ 1			✓ 1		✓ 2	
9	26	2/6		✓ 1		✓ 1				✓ 1	✓ 1
9	27	1/4				✓ 1					✓ 1
10	28	3/5		✓ 2		✓ 1				✓ 2	✓ 1
9	29	5/7		✓ 4		✓ 1			✓ 3	✓ 1	✓ 1
Total observations featuring code (n = 29)			13	26	10	10	3	14	14	20	12

Side Effects

This category considered the way that side effects were introduced, described and advised on. An overview of the codes indicated for side effects over the 29 consultations is provided in Table 3. We found that side effects were discussed in the majority of consultations (26/29), often with qualifying statements (verbal qualifiers) that indicated the certainty or likelihood of the side effects. For example: *"just to make you aware of some of the common side effects. Most*

people tolerate it well". Eight of the 29 consultations included side effects with numerical qualification "*60–70 percent of people tolerate it well*" OR *"I would say we're talking about the common symptoms, one in ten. So, ten people given the medication, one would experience, nine would not."*.

In terms of the magnitude of side effects, the most common code was *not serious/minimising*, which featured in 18/29 consultations e.g. *"You'll also have a leaflet to read, but I wouldn't get too worried about all the list of side effects there. Because some people get really worked up, because any medication will come with a list of side effects".* Although this was closely followed by *serious /emphasising* in 15/29 consultations and *Not serious* featured in 10/29. As such, its notable that magnitude is being described in a variety of ways within one consultation. This is because different levels of seriousness are considered to be associated with different side effects – for examples it could be considered that gastro related side effects are less serious than cardiac side effects. For example: less serious side effects *"Many people can you know feel sick, feel Nauseous, they can actually vomit, you know, and they can have diarrhoea,"*, and more serious side effects "*donepezil, can affect the heart rate, it can lower the heart rate, which can increase the risk of her feeling dizzy and you know, increase the risk of falls or collapse"*

The code applied most to descriptions of the likelihood of side effects was *Some side effects/few people don't tolerate*, which was featured in 22/29 consultations e.g. *"Most people tolerate it well, so you might not experience any"*

Descriptions of the mitigation of risk was assessed. Most consultations featured a professional plan for the mitigation of risk, that is how to engage healthcare services if there is an issue with side effects (23/29). The nature of side effects was most commonly described as gastric (25/29) or neural (23/29).

Finally, when it came to referring to evidence for side effects, 12 of the 29 consultations included reference to personal experience e.g. "*but I have had people - they couldn't bear it. They felt a burning sensation. They felt nauseous and these things. So they contact me. Usually, people settle after a few days but sometimes people can't bear it*." Five consultations included reference to clinical trial data.

Clinician	Patient		Side Effects						
			Side effects mentioned				Magnitude of effect		
			Side effects with numerical qualification	Side effects with verbal qualification	Side effects with no qualification	Not mentioned	Not serious/minimising	Moderate	Serious/emp
1	1	3/7	✓ 1	✓ 2	✓ 1			✓ 2	✓ 1
1	2	5/9		✓ 2	✓ 3		✓ 1	✓ 1	✓ 2
1	3	3/7		✓ 1	✓ 1		✓ 1		
2	4	3/6		✓ 1	✓ 1	✓ 1		✓ 1	✓ 1
2	5	1/6		✓ 1				✓ 1	
2	6	2/6		✓ 1	✓ 1				
3	7	3/6		✓ 1	✓ 2			✓ 1	
4	8	2/5	✓ 1	✓ 1			✓ 1	✓ 1	
4	9	6/11	✓ 1	✓ 3	✓ 2			✓ 4	✓ 1
4	10	3/8		✓ 1	✓ 2		✓ 1		
4	11	4/8		✓ 1	✓ 2	✓ 1	✓ 1	✓ 2	✓ 1
5	12	2/8		✓ 1		✓ 1		✓ 2	
1	13	2/7		✓ 1	✓ 1		✓ 1		✓ 1
6	14	5/12	✓ 1	✓ 3	✓ 2		✓ 1	✓ 1	✓ 2
6	15	6/7		✓ 6			✓ 2	✓ 2	✓ 2
6	16	4/8		✓ 2	✓ 2		✓ 1	✓ 2	✓ 1
6	17	5/11	✓ 1	✓ 2	✓ 2				✓ 4
6	18	3/7	✓ 2	✓ 3				✓ 2	
7	19	3/7	✓ 1			✓ 1			✓ 1
7	**20**	2/4		✓ 1	✓ 1			✓ 2	
8	21	3/7	✓ 1	✓ 1			✓ 1		
7	22	2/7		✓ 1		✓ 1			✓ 1
6	23	3/6		✓ 2	✓ 1				✓ 3
7	24	4/4		✓ 2	✓ 2			✓ 2	✓ 1
9	25	2/5			✓ 1				
9	26	1/6		✓ 1				✓ 1	
9	27	0/4							
10	28	4/5		✓ 2				✓ 2	✓ 1
9	29	1/7		✓ 1				✓ 1	
Total observations featuring code (n = 29)			8	26	17	5	10	18	15

Treatment Plan

The codes assigned under the category of treatment plan referred to any discussion of treatment planning and prognosis, including discussion and justification of treatment options – outlined in Table 4. As previously indicated, treatment plan information featured heavily in the consultations – with around 70% of the dialogue (context units) in each consultation featuring this.

Treatment mechanism (i.e. how the treatment works on the brain), was discussed in only 13/29 consultations. eight consultations included descriptions of the treatment mechanism in a patient-friendly way e.g. “the treatment is looking at correcting the chemical balance”, and in five of the consultations the

mechanism was described with jargon “the chemical’s called acetylcholine. It helps with the memory function. So, what the medication does is, it increases that transmitter, that chemical in the brain artificially. So, it makes it more available. It doesn’t produce anymore that what you’ve already got, it just makes it more available to the brain.” In the remaining consultations there was no discussion of how the treatment worked.

The rational or justification for the treatment being offered was considered in around half (15/29). For example, “We are thinking of a treatment called donepezil which is best for the type of dementia you have”. In contrast, in the majority of the remaining consultations (11/19), a named treatment was introduced without rational e.g. “The medication we are prescribing today is called donepezil” .

There was a high degree of consistency across the consultations with regards to discussion of the titration plan for the medication (24/29), For example: “So, it’s started as a 5 milligram once a day dose. In the first week it’ll stay as 5 milligrams. In the second week, it goes to 10 milligrams once a day. In the third week it becomes 15 milligrams and in the fourth week it becomes 20 milligrams, once a day again.”

In half of the consultations a risk/benefit balance was explicitly discussed (15/29), e.g. “it’s not a cure for the disease and we don’t want to give you something which causes lots of, you know, side effects or issues to you. So, it’s a balance of risks versus benefits.”. Prognosis was discussed In around a third of the consultations, with 4 of the 29 consultations including timescales when discussing this: “And these treatments are notably effective as long as 18 months to 3 years. But I've seen people to remain stable even as long as 5 to 7 years. It’s going to depend on how your body is going to respond to this medication as well.”.

Personalisation of treatment plan featured in a third of consultations (10/29), typically this happened with reference to history or side effects e.g. “given, given your kidney function and your age, we might have to do it fairly slowly.”

We also examined whether patients were offered choice and their understanding of the discussion: Recognition of patient choice most occurred by invitation to comment (18/29) e.g. “Is that OK?”. Requests for more information were identified in in half (15/29) of the consultations e.g. “What does this do to me?”. In addition, relative felt the need to provide additional explanations to patients in 19/29 appointments: “He said, after the tests and the brain scan, they think that there’s some shrinkage in the brain that means that there are problems there. And they think it’s Alzheimer’s”.

Clinician	Patient	Number units mention TP	Treatment Plan								
			Treatment Mechanism				Treatment Rationale				Titrati
			mechanism is explained with detail	mechanism is explained with jargon	mechanism is explained in a patient friendly way	no mention of how treatment works	a range of treatment options are presented with a. rationale for the chosen treatment	treatment is offered with some rationale for treatment	named treatment is given with no rationale	no name no rationale	Titrati plan indica
1	1	6/7				✓ 6		✓ 1	✓ 1	✓ 4	✓ 1
1	2	8/9				✓ 7				✓ 8	✓ 1
1	3	5/7				✓ 5				✓ 5	✓ 1
2	4	5/6				✓ 5	✓ 1			✓ 4	✓ 1
2	5	2/6				✓ 2		✓ 1	✓ 1		✓ 1
2	6	2/6				✓ 2				✓ 2	✓ 2
3	7	3/6		✓ 1		✓ 2		✓ 1	✓ 1	✓ 1	✓ 1
4	8	3/5			✓ 1	✓ 2				✓ 3	✓ 2
4	9	9/11			✓ 1	✓ 8		✓ 3	✓ 3	✓ 3	✓ 3
4	10	6/8				✓ 5		✓ 3	✓ 1	✓ 2	✓ 2
4	11	4/8			✓ 1	✓ 3				✓ 2	✓ 2
5	12	3/8	✓ 1			✓ 2		✓ 1		✓ 2	✓ 1
1	13	4/7			✓ 1	✓ 3		✓ 1		✓ 3	✓ 1
6	14	8/12		✓ 1		✓ 7		✓ 1	✓ 2	✓ 4	✓ 1
6	15	6/7			✓ 1	✓ 4		✓ 1	✓ 1	✓ 4	✓ 2
6	16	7/8				✓ 7			✓ 1	✓ 6	✓ 3
6	17	8/11				✓ 8		✓ 1		✓ 6	
6	18	4/7				✓ 3				✓ 3	✓ 2
7	19	5/7				✓ 4			✓ **1**	✓ 3	✓ 1
7	**20**	3/4				✓ 3			✓ 1	✓ 1	✓ 1
8	21	6/7				✓ 6				✓ 6	✓ 2
7	22	6/7				✓ 6		✓ 1		✓ 5	✓ 2
6	23	4/6				✓ 3				✓ 3	✓ 1
7	24	4/4			✓ 1	✓ 3				✓ 4	✓ 1
9	25	3/5		✓ 1	✓ 1	✓ 2				✓ 3	✓ 1
9	26	3/6		✓ 1		✓ 1		✓ 1		✓ 2	
9	27	4/4/				✓ 4		✓ 1		✓ 3	
10	28	3/5		✓ 1		✓ 2		✓ 1		✓ 2	
9	29	5/7			1 ✓	✓ 2		✓ 3	✓ 1		
Total observations featuring code (n = 29)			1	5	8	29	1	15	11	27	24

Discussion

This study aimed to explore how pharmacological treatments for dementia are presented and discussed in memory assessment services, focusing on presentation of the benefits (treatment purpose and treatment effect), side effects and treatment plans. Overall, our findings indicate that there are some commonalities in the ways that benefits were communicated; a focus on symptom management and symptom improvement was present across the 29 consultations.

The finding that clinicians were more likely to present the benefits in terms of symptom improvement, rather than (or in addition to) a reduction or delay of symptom progression may represent a form of *positive framing*. The influence of positive framing has long been explored in medical communication – in which information is presented or framed as a gain (e.g improvements), as opposed to a loss (e.g. absence of improvement)[16].

In our study we found that benefits of medications were presented overwhelmingly as symptom improvements, with **likely** benefit. If we refer back to the trials data of donepezil, a positive frame should indicate symptom improvement or delay of progression in **around half** of those treated[4] - and it would be just as accurate to report around half patients seeing no benefit.

There is evidence that discussions about poor prognosis without the option of hope can be challenging for clinicians and patients[17]. This can result in communications being more optimistic and potentially more persuasive as presenting treatments as gain framed benefits result in people being more likely to take the treatment[18]. With the lack of curative treatments available, presenting the benefits in this way offers hope in the face of an otherwise challenging prognosis. This culture may be echoed in societal perspectives that have shifted from biomedical views on dementia as a disease to cultures in which 'living well with dementia' is readily endorsed and supported.

Furthermore, in our study the verbal qualifiers used regarding the likelihood of benefit were rated as medium 21/29 or definitive 19/29, which could also misrepresent the uncertainty and complexity of potential outcomes based on what we understand of the efficacy based on trial data[4].

In considering why clinicians might approach the communication of benefits in thus way - our findings are consistent with the positive framing bias, seen else where on the literature[18]. Clinicians may also struggle to hold accurate representations of the benefits of treatments they recommend, with clinicians more frequently overestimating benefits of treatments[19]. The breadth and depth of the medical literature is extensive and can be difficult to have at a clinician's fingertips[20]. Evidence suggests that training about how to communicate risk and benefits is limited[21]. Furthermore, the nature of clinical training is such that a doctor's default 'script' for describing medication effectiveness is most likely influenced by practice-based mentors and peers rather than directly from published research and (as our related findings suggest[13]). This can be problematic if inherently the scripts are biased in framing – but also for new medications where "scripts" and experience will not be established. This speak to the issue of improving risk benefit communication identified earlier[10], and the necessity that clinicians are educated and informed about risk sufficiently to facilitate decision making for the patient.

In the context of current dementia treatments, where side effects are minimal, this positive framing may not in itself be problematic or lead to unreasonable outcomes in terms of being inherently persuasive. However, there is the risk that this approach could interfere with shared decision making if it affects if unduly persuasive or contrary to the beliefs of the individual and their relatives or does not meet the threshold for effective communication of the facts. Taken together, the findings point to recommendations for support for clinicians to be able to identify and interpret clinical trials data to be able to discuss it with patients and their families. Furthermore, clinicians should be supported to understand evidence based communication methods that can help people to understand efficacy data more accurately and effectively, as a precursor to enabling shared decision making. Recommendations might include understanding the impact of gist communication and using positive frames/loss frames appropriately to personalise message and facilitate SDM, using visuals or patient decision aids as support for clinicians as well as patients.

Strengths and limitations

This study recruited actual patients, relatives and clinicians as participants from two cities in North England. Across 29 transcripts, we observed the experiences of people with a range of demographics. However, our sample size did not allow for analysis of the potential impact of any patient factors. For example, it would be useful from a clinical perspective to understand whether more personalisation is given to certain groups of individuals. Comparison between younger and older patients, patients with and without family members present, and those whose first language is not English, would help to ensure that there is no differentiation of experiences by patient factors. Individual doctors may also have had different communication styles regarding treatment benefits, which was not explored in this study.

The main strength of the study is that we recorded and analysed actual clinical consultations, rather than being dependent on patient or clinician recall or reflection on consultations, which can be subject to error and bias. All participants knew that consultations were being recorded and it is possible that what they said or did was in some way performative or heightened. However, the camera was inobtrusive and, furthermore, the actions and speech of participants in the consultations, which were of some significance to those involved, does not suggest that we recorded anything other than expected behaviours.

Conclusions

Our findings are timely given the newly licensed and expected medicines for dementia and the additional challenges that there are around communicating them to patients, compared to treatments established in practice for 20 years or more. The weighing up of the benefits and side effects of disease-modifying treatments is exemplified by them being approved and offered in some countries and not in others, and most recently being approved by the UK regulatory authorities but being seen as too risky or problematic to introduce into existing pathways to be approved by NICE for the state health service.

Declarations

Ethics approval and consent to participate

Ethical approval for the study was gained from the National Research Ethics Service [details **Yorkshire & The Humber - Bradford Leeds Research Ethics Committee** reference 21/YH/0032] on 8.3.21.

Consent for publication

No personal individual data is presented. Participants consented to use of direct quotes from transcripts to be used in publication.

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Author Contribution

SJS was the PI for the study and was involved with formulating the research question(s), designing the study, carrying it out, analysing the data and writing the article. RK was involved in designing the study, carrying it out, analysing the data and writing the article. AWG was involved in study design and carrying it out. JD, RD, GR, and PK were involved in designing the study and writing the article.

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Data Availability

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

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Figures

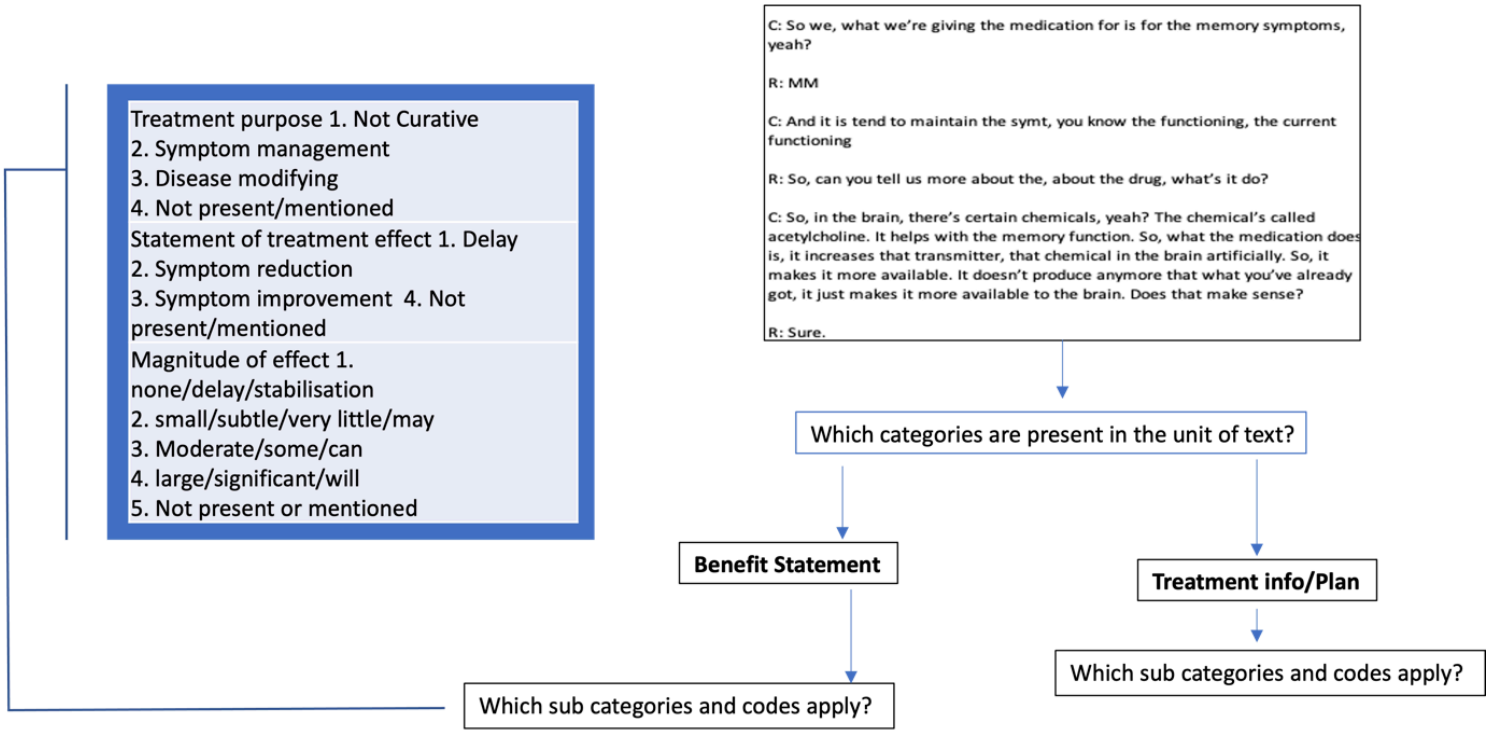


Figure 1

Process of applying the codebook to the context units