FULL/LONG TITLE OF THE STUDY
Improving triadic decision-making involving people with dementia

SHORT STUDY TITLE / ACRONYM

Making decisions whilst living with memory problems

PROTOCOL VERSION NUMBER AND DATE

Protocol Version 3.0 20 June 2023

RESEARCH REFERENCE NUMBERS

IRAS Number:	321260
SPONSORS Number:	STH 22002
FUNDERS Number:	NIHR 150756
REC Reference	23/WA/0147

VERSION CONTROL

Version	**Date**	**Amendments**
Version 1.0	24 March 2023	Final version of protocol.
Version 2.0	30 May 2023	Added end of study definition (Section 5).
Version 3.0	20 June 2023	Full title changed to match the NIHR funding title, version control table added.

KEY STUDY CONTACTS

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Sponsor	Sheffield Teaching Hospital NHS Foundation Trust
Funder(s)	NIHR Health and Social Care Delivery Research (HSDR) Programme

STUDY SUMMARY

Abbreviations used in this document

ACE	Addenbrooke's Cognitive Examination
CA	Conversation Analysis
HCP	Healthcare professional
PIS	Participant Information Sheet
PPI	Patient and Public Involvement
PwND	Person/people with neurodegenerative cognitive disorder (eg., dementia)
RA	Research Associate
RDaSH	Rotherham, Doncaster and South Humber NHS Foundation Trust
SDM	Shared decision-making
STH	Sheffield Teaching Hospitals NHS Foundation Trust

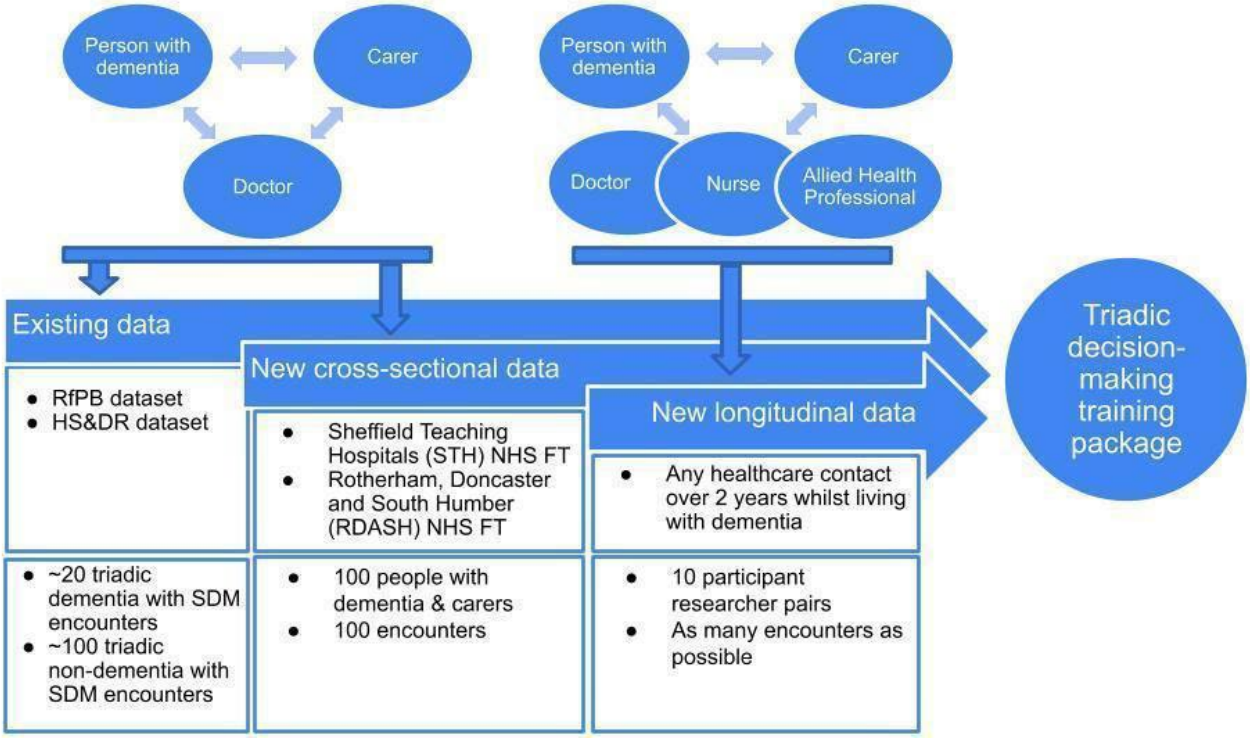
KEY WORDS: conversation analysis; dementia; multiparty interaction; shared decision-making; memory

Study Title	Improving triadic decision-making involving people with dementia

Internal ref. no. (or short title)	Making decisions whilst living with memory problems
Study Design	Qualitative research
Study Participants	People living with neurodegenerative cognitive disorders
Planned Size of Sample (if applicable)	100 dyads across 2 sites x 1 interaction; 10 co-researcher participant dyads working alongside the research team to collect videorecorded data for up to 2 years
Planned Study Period	4 years
Research Questions	1) What communication strategies are healthcare professionals and carers using to involve people with neurodegenerative cognitive disorders in decision making? 2) How do people with neurodegenerative cognitive disorders respond to these in the consultation?
Research aims and objectives	There are 4 key research aims: 1. To contribute to the evidence base about how decision making takes place in triadic environments 2. To compare findings on decision making in triadic medical encounters involving patients with and without neurodegenerative cognitive disorders 3. To identify the most effective and appropriate strategies for involving people with neurodegenerative cognitive disorders (PwND) in decisions about their medical care, especially as the disease progresses 4. To disseminate these findings to healthcare professionals (HCP), PwND and carers in an effort to increase patient involvement in decision-making about their care And 6 study objectives: 1. Provide a detailed analysis of the communicative strategies used in triadic consultations and compare those involving patients with or without neurodegenerative cognitive disorders (Aim 1) 2. Identify how these strategies can support or limit shared decision-making for PwND (Aim 1, 2) 3. Use both cross-sectional and a novel longitudinal PwND/carer co-researcher design to describe how the

	meaning of shared decision-making for PwND evolves and communicative strategies used change as the disease progresses (Aim 2, 3) 4. Test the hypothesis that living with a neurodegenerative cognitive disorder is a 'transformative experience', and the authentic values of PwND change as the disease progresses (Aim 3) 5. Construct educational resources and decision support tools to enable shared decision making for PwND (Aim 4) 6. Disseminate results to PwND and all involved in working with and caring for them (Aim 4)

STUDY FLOW CHART



ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITTEES & GROUPS

PPI

We have 4 PPI co-applicants who have been/will be involved in assuring that the study is relevant and that our communication with research participants and any documents intended for dissemination of the findings to service users are understandable and accessible to potential participants. Our PPI co-applicants will help to design documents such as the PIS and consent forms, and help us to identify innovative ways of approaching potential participants to ensure optimal understanding of our research plans and truly informed consent. These co-applicants will also be involved in the dissemination phase to ensure that the findings get to the appropriate user groups/stakeholders and are communicated in ways that are acceptable, accessible and meaningful to lay audiences.

The inclusion of experts by experience as co-researcher participants in the third part of our study will provide for participant and public involvement and offer additional oversight of the data collection process. We will also be meeting quarterly with our PPI co-applicants to report on data collection and analysis.

In the early design stages of the project, we consulted with the charity DonMentia (which is comprised of people with dementia and their partners). We have been invited to regularly attend their meetings and present updates on the research on a regular basis. This group is well-versed in providing feedback to researchers, and assisted us in the drafting of the research proposal. We also received valuable feedback (eg., to use words like ‘choices’ instead of ‘wishes’) from the South Yorkshire Dementia Research Advisory Group (DRAiSY) who were particularly enthusiastic about the longitudinal arm of the study (including the element of video recording).

Study Steering Group

We have set up a study steering committee with 5 independent members (of six members in total), one of whom is a PPI member recruited through the NIHR’s People in Research website. This project uses exclusively qualitative methodology, similar to an approach which has been used in previous studies led by one of the co-PIs (Prof Markus Reuber) and funded by the NIHR. The Steering Group will also serve as our internal Data Monitoring and Ethics Committee (in addition to all aspects of the study being subject to external inspection and oversight by the sponsor and regulatory bodies). A separate Data Monitoring and Ethics Committee is not necessary as our study is purely observational and as the kind of data we will be collecting and analysing is not intrusive. None of the study procedures put participants at any significant risk.

STUDY PROTOCOL: Improving triadic decision-making involving people with dementia

Short lay summary:

Most care decisions involving people with neurodegenerative cognitive disorders (PwND) are made in interactions involving three parties: the PwND, their carer, and a healthcare practitioner (HCP). This study explores two gaps in knowledge: how decisions are made when three parties are involved, and how decisions are made when one of those parties has cognitive difficulties. The study aims to describe how best to involve PwND in decision making as much as possible, for as long as possible.

We focus on the following questions: What communication strategies are HCPs and carers using to involve PwND in decision making? How do PwND respond to these? Our study will apply Conversation Analysis (CA) to existing and new datasets, in the form of 3 workpackages.

WP1: Analysis of extant recordings of triadic interactions between neurologists, patients and accompanying persons from previous studies collected in outpatient clinics in Sheffield.

WP2: Collect and analyse a new cross-sectional database of 100 new recordings of clinical encounters between patients who have or subsequently receive a diagnosis of neurodegenerative cognitive disorder, their carers, and HCP.

WP3: Recruit 10 PwND and their carers from WP2 as participant-researchers, to record their medical appointments (eg., with dementia nurses, occupational therapists, GPs) for up to two years. This will allow us to compare interactions with different HCPs and analyse both changes in PwNDs' contributions and in the role of accompanying persons over time. The team will engage both PwND and their carers in deciding what encounters to record, as well as explore their perspectives on when and how they (both) were involved successfully in shared decision-making.

Our outputs will include online training packages, short videos and leaflets. Those for carers will help them support PwND in decision-making, and those for HCP will help ensure that PwND are given every chance to express their choices when making decisions.

1 BACKGROUND

People should be offered the chance to participate in decisions about their health, and people with neurodegenerative cognitive disorders (PwND) have the same rights to autonomy and self-determination as anyone else [1]. However, while the NHS constitution and GMC direct clinicians to ensure the participation of PwND in decision making [2,3], little advice is provided on how this can best be achieved when the patient's capacity is reduced. Additionally, PwND typically bring someone else along to medical appointments [4], and some of the decisions that need to be made directly involve third parties (such as partners or carers). Most care decisions are therefore made in triadic interactions (conversations involving three parties): the PwND, healthcare professional (HCP) and the PwND's carer, meaning that decision making is a triadic process.

This study addresses the problem of how PwND can be more fully involved in decisions about their own care. NIHR-funded research [5] calls for better involvement of PwND in triadic decision making. While most PwND want to be involved in decision making about their own care [1,6], the involvement of carers in such processes can be helpful: for instance, they can clarify the history, and help ensure that decisions that have been made are recalled and executed. Carers can also support PwND in expressing their desires, values, and preferences even when they may lack decision-making capacity or the means of communicating their ideas clearly. Previous research on triadic medical encounters shows that the presence of a third party (in addition to the HCP and the patient) does not negatively affect the amount or content of patient contributions, nor the level of attention they receive from the HCP [7,8]. In fact, it has been shown how companion contributions can be beneficial, i.e. by introducing important information into the interaction, or supporting the patient [9,10]. However, in relation to PwND it has also been demonstrated that carers may overlook the wishes of PwND and take over decision making [11], speaking for or about PwND rather than supporting them to speak for themselves [12]. This silencing of PwND can create problems for both the PwND and their carers when the experiences of PwND are distorted, and PwND are often treated as less competent than they are [13].

Furthermore, carers and PwND are not always aligned in their decision making around courses of treatment or other care decisions [11,14,15]: carers and PwND may differ in what they see as a ‘reasonable decision’ [16], and PwND may lack understanding of future changes to their condition [17]. This lack of ability to understand or accept the changes in their circumstances is one of the problems in involving PwND in shared decision making (SDM) [18]. As time passes, PwND may become unable to articulate personal information and caregivers may need to be helped effectively to engage in healthcare appointments on the PwND’s behalf [15]. A detailed ethnographic study of triadic shared decision making in acute settings highlighted the difficulties in involving PwND in decision making due to the lack of timely and consistent engagement with the person by the care team, the effect of being taken out of their normal, known environment on the PwND’s behaviour and presentation, and the general lack of knowledge about the PwND’s understanding of their current situation [19; see also 20].

Legal and professional guidance on decision-making with PwND states that carers should only be involved insofar as they help HCPs understand the PwND’s past and present views, or what would influence their decisions if they had capacity [2]. Existing legal frameworks thereby focus on protecting the interests of the patient and may not take full account of the consequences care-related decisions could have for others [21]. This is particularly relevant in neurodegenerative cognitive disorders, where carers might be directly affected by decisions about care provision (e.g. through refusal of formal carer support); or genetic testing (in inherited dementias). Our research will show how HCP can improve communication with PwND by taking optimal account of their views, and by involving carers when appropriate.

Existing NICE guidance on involving patients in decision making is not tailored for interactions involving PwND, and is based on research on two-party encounters [22,23] rather than the triadic decision making processes which are typical for healthcare encounters with PwND [4,24]. Prior work by this study’s joint lead applicant has highlighted how much of a difference the presence of a third party makes to interactions between patients and HCPs [25]: Several groups of patients - in addition to PwND - are routinely accompanied to their appointments, for instance older adults without cognitive impairment [26], children [27], and adults with intellectual disabilities (ID) [28,29].

The similarities with interactions involving PwND are likely to be greatest with studies focusing on conversations involving adults with intellectual disabilities (ID), whose cognitive abilities are affected. When providing health information to adults with ID, HCPs need special skills in conducting three-way interactions [29], but little information about what these skills are or how they can be developed exists. Previous research exploring decision making and the deployment of choice in interactions involving adults with ID has characterised the difficulties that need to be overcome [29, 30]. These studies use the method of Conversation Analysis (CA) to analyse how actual, real-life decision-making interactions are conducted.

A focus on actual medical interactions is increasingly advocated for understanding and improving healthcare [31,32], reflecting the mounting evidence that the precise wording used in a particular setting can make a big difference to the outcome of the conversation. A comparison of two closing questions used by GPs, “is there ANYthing else" vs."is there SOMEthing else you want to address today?" found that in response to “anything”, patients were no more likely to express additional concerns than if the question was not asked at all. In contrast, “something” eliminated 78% of unvoiced concerns (odds ratio=.154, p=.001) [33].

Current work in this tradition includes two projects led by the co-PI: An RfPB-funded study (PB-PG-0211-24079) showed how conversational markers can support the differentiation of neurodegenerative and functional memory complaints. It took account of third party contributions but did not focus on decision-making [4,24]. An HSDR funded study (10/2000/61) demonstrated how HCPs can ensure patients know they have choices in clinic conversations [22] but did not focus on triadic environments or individuals with cognitive impairment. Our proposed research will use the same tried-and-tested methodology to build on these studies, and focus on decision-making involving PwND in a triadic medical environment.

CA has been successfully used to develop a variety of training packages, which will help underpin our public- and clinic-facing outputs. These range from training schemes designed to improve everyday communication (eg.,The Conversation Analytic Role-play Method (CARM [68]); to diagnostic aids (eg., for the diagnosis of epilepsy [69]; and for the differential diagnosis of functional and neurodegenerative memory disorders [4]); to therapeutic interventions aimed at (eg., improving communication between people with aphasia and their partners, [70]). The CA-based Better Conversations intervention training package [70] has been extended to various subtypes of aphasia, and the NIHR is currently funding another study extending the Better Conversations model to neurodegenerative cognitive disorders.

The outputs from this project will build on these successes which, like our study, all have a conversation analytic base. However, all the training and diagnostic packages described rely on the analysis of only the patient’s speech, or of a dyadic interaction. This highlights the crucial difference between past work and our study - we are focussing on three-party conversations, which have a different underlying structure and a different set of turn-taking rules. The main aim of our first work package is to understand how triadic interactions differ from dyadic ones, and this basic understanding will then inform all the following work in the project.

2 RATIONALE

Dementia affects 944,000 people in the UK and is projected to rise to 1.1 million by 2030, and 1.4 million by 2040 [34]. As the disease progresses it becomes harder for PwND to communicate what they want and need, and ever more important to ensure an optimal transfer of information between PwND, carers and HCPs. Acknowledging public concerns and the continuing need for a better understanding of dementia, one of the most feared and stigmatised health conditions [35], the HS&DR has published a highlight notice for dementia to which this project is a direct response. Another NIHR-funded study has recently highlighted the importance of better involvement of PwND in conversations about their care [5]. Our research will help with this by showing clinicians and carers how they can optimally involve PwND in important decisions about their own lives and thereby contribute to improving the health and wellbeing of both, PwND and their carers, two populations specifically identified as currently underserved by research [36].

PwND and their carers have to make many decisions about investigations and treatment related to their neurodegenerative cognitive disorders, and also about common comorbidities such as arthritis, hearing problems and heart disease [37]. As neurodegenerative cognitive disorders progresses, carers are likely to experience increasing pressure to get involved in decision-making or to take over decisions which the PwND would normally make themselves. This is at odds with the increasing emphasis on self-care, and on supporting people with neurodegenerative cognitive disorders to live independently as long as possible. Therefore our research is particularly timely as it will investigate how HCP can best involve PwND and their carers in such decisions, especially as the PwNDs' views may change as they become more disabled by their condition.

Our study will examine real life decision-making among HCP, PwND and their carers to find examples of best practice, and use these to develop training materials to enable PwND to better exercise their rights and participate in making choices about their care. People have the right to reach their own decisions regarding their health and care needs [1,2]. This right extends to all individuals with decision-making capacity [3]; for decisions where individuals lack capacity, those caring for them should make the decision in their overall best interests. Importantly, such best interests are determined not solely in terms of their medical interests, but with reference to their past and present wishes and feelings, and the beliefs and values that would have influenced them in coming to a decision had they had the capacity to make it [38].

While cognitive impairment can (though does not necessarily) affect the capacity of PwND, they may still be able to articulate authentic values that can be brought into the decision-making process; indeed, qualitative research involving PwND highlights that PwND can reliability report values and preferences even in moderate to severe stages of the condition [11]. Acknowledging the importance of supporting authentic decision-making – even in situations of impairment of capacity – has led to the rise of the person-centred care model for PwND [39, 40] operationalised in the shared decision-making (SDM) model [11,41]. While there is no universally-agreed definition for SDM [41], PwND interpret it as 'supporting' (rather than taking over) their participation in decision-making, 'hanging on' (versus letting go) to situations where they do maintain decision-making capacity, and 'being central to' (rather than being excluded from) making decisions [42].

Although we know that PwND perceive SDM positively [43-45], we still do not know just how SDM is, or should be, done. We lack concrete examples of what type of language use counts as 'supporting' participation; as 'hanging on' to situations where PwND retain capacity; as PwND 'being central to' rather than excluded from decision making. Instead, research to date mostly has relied on descriptions of SDM collected after the fact. Questions and topics such as those reported in [45] about what information was provided, what prompted the decision, what was the decision, did you reach it together, what were the alternatives are all excellent questions, but they require participants to recall events that have already happened. Instead, our study aims to capture what is said in decision-making conversations and to analyse the language used. Our study will examine the detail of the language used to accomplish SDM (or show when it is not achieved), and this information can be used to provide concrete guidance for future encounters.

This particular gap in our understanding of the language used to implement SDM stems from the methodologies employed in previous research. Most studies of triadic medical interactions have taken a quantitative coding approach (eg. [26]), although the relevance of this is limited in decision-making, which is clearly sequential. Methodologies such as Conversation Analysis (CA), which focus on interactional aspects of discourse, are better-suited for studying how decisions evolve. CA is a qualitative, micro-analytic method for studying real-life interaction widely recognised as the leading methodology for investigating doctor-patient communication in practice [31,32]. Our own previous research has demonstrated how CA-derived insights can be the basis of an online learning resource judged to be capable of changing clinical practice and recommended by NICE [23,46].

Our proposed study will use this proven CA-methodology to investigate how clinicians design questions or present choices when there are two potential respondents, one of whom is a PwND. Explicit attention to the triadic nature of the consultations is important because the structure of conversation, in particular turn-taking, differs when more than two parties are involved. Most research to date involving PwND has concentrated on just two parties out of the three that are present in most encounters, eg., the 36 papers reviewed in [11], [17].

Researchers have begun to include PwND in the design and conduct of the research itself, not only as participants. PwND have been involved as participatory researchers to investigate ways in which a discussion tool about risk could be made more acceptable to PwND[18]; an ethnographic study involves PwND as equals alongside carers and HCPs [19]. Other NIHR-funded research [5] calls for greater involvement of PwND in triadic decision making. To address these goals, our study will engage a PwND and a carer as PPI co-applicants, and also contains a longitudinal component with 10 participant researcher dyads recording their interactions with healthcare professionals such as GPs and nurses.

3 THEORETICAL FRAMEWORK

The recognition of people's right to make their own decisions regarding their health and care needs [2,3] is grounded in the principle of respect for autonomy, which maintains that individual persons should be able to act freely in accordance with a self-chosen plan [47]. Three broad arguments are usually levelled in support of this principle [48]. One line of argument, owed to the utilitarian philosopher JS Mill, holds that permitting individuals to exercise free choice promotes the utility of all, by helping individuals to develop their capacities for reason, fulfil their own ideas of the good, and demonstrate 'experiments in living' that may display to others differing visions of individual and social welfare. Another draws from Immanuel Kant's categorical imperative, in its Formula of Humanity, that entreats moral agents to treat other humans, not merely as means, but as ends in themselves [49]; more precisely, according to Kant it is the human capacity to determine our own values and desires that give us all reason to act, and we ought therefore to treat others' values with the respect we show our own [50,51]. Lastly – least explicitly argued for, but comprising part of the 'background constellation of values' widely accepted in contemporary medical ethics and law [52,53] – is the assumption of 'liberal neutrality', that there is intrinsic value in people being permitted to frame and pursue the good in their own way.

Understanding autonomy – and thus decision-making – in this fashion has important implications for the care of PwND. On all of these justifications of the principle of respect for autonomy, it is not simply the fact of being able to make decisions (decision-making capacity) that is important, but also that these decisions reflect what is most important to the person (decision-making authenticity).

Further philosophical insights into autonomy – and its implications for person-centred care and SDM – shape our framing of decision-making. The first is that autonomy is relational – social relationships can support or undermine autonomy [54]. Relational autonomy highlights that, for all people, our ability to articulate authentic values, exercise decision-making capacity, and express those choices, show interpersonal material, cognitive, and affective dependencies that can support or undermine these abilities [55,56,57]. For PwND, supportive social relationships can help them express treatment-related values, and to adhere to decisions made on the basis of those values, in the context of major healthcare decisions such as cancer treatment [58]. PwND identify the relationships that help them remain involved in SDM [11], and spouse-carers participate in SDM in ways that support [42] or 'manage' [59] the autonomy of PwND. However, such social relationships can also undermine the autonomy of PwND. A focus on capacity (over authenticity) can deprive PwND of the opportunity and support required to articulate their values [58,60]; carers can misidentify preferences [61] and can exclude PwND from decision-making when their only cognitive impairment is only mild [11].

A second core feature of respect for autonomy and SDM for PwND is that it is a temporally-extended process. While ethical dilemmas in healthcare are often framed in terms of the "punctate decision" – a specific act or choice, considered in isolation from the rest of a person's care [62] – the degree to which PwND can participate in these decisions depends upon: the ways in which other participants in SDM have attempted to understand PwND's preferences; the encouragement they have received to participate in SDM; or development of relationships that enhance or undermine PwND's confidence in their ability to express their values [63,64].

The third, related, consideration is that our authentic values may change over time, and indeed that neurodegenerative cognitive disorders itself may be a transformative experience [66]. Transformative experiences are those that not only change our authentic values, but do so in a way that is difficult to predict from before we have undergone the experience [66]. PwND may undergo just such a transition. As Wendy Mitchell, an author writing after a dementia diagnosis, put it in writing to her former self:

> *We wouldn't get on now, you and I. Too much time has passed. We are friends who have lost touch, who now lead parallel lives. We like different things. (Mitchell 2018)*

This entails that expressed preferences of a PwND prior to the clinical onset of their condition do not necessarily express their present authentic preferences. SDM for PwND therefore requires attention to the person as they are now – and how that may differ from their former selves – rather than sole adherence to previously-expressed wishes (e.g. in the form of advance directives) [65].

This understanding of respect for autonomy – as relational, temporally-extended, and potentially transformative – underpins our framing of decision-making by and for PwND. We do not invoke a particular theoretical model of decision-making [67], since Conversation Analysis provides tools for a fine-grained analysis of different ways in which decisions are reached, and different approaches may be relevant in different contexts – and indeed, highlights that not all parties necessarily even agree on which points of a conversation represent 'choices' at all [22]. Instead, we aim to identify conversational and interactional practices that can support person-centred care, understood in terms of making decisions that reflect PwND's authentic values and preferences [39,40].

4 RESEARCH QUESTION/AIM(S)

The overall goal of the study is to analyse the strategies used by all parties in triadic interactions to either open up, or close down, opportunities for involvement of the PwND in decision making about their own care.

There are 4 key research aims:

1. To contribute to the evidence base about how decision making takes place in triadic environments
2. To compare findings on decision making in triadic medical encounters involving patients with and without neurodegenerative cognitive disorders
3. To identify the most effective and appropriate strategies for involving PwND in decisions about their medical care, especially as the disease progresses
4. To disseminate these findings to HCP, PwND and carers in an effort to increase patient involvement in decision-making about their care

And 6 study objectives:

1. Provide a detailed analysis of the communicative strategies used in triadic consultations and compare those involving patients with or without neurodegenerative cognitive disorders (Aim 1)
2. Identify how these strategies can support or limit shared decision-making for PwND (Aim 1, 2)
3. Use both cross-sectional and a novel longitudinal PwND/carer co-researcher design to describe how the meaning of shared decision-making for PwND evolves and communicative strategies used change as the disease progresses (Aim 2, 3)
4. Test the hypothesis that neurodegenerative cognitive disorders is a 'transformative experience', and the authentic values of PwND change as the disease progresses (Aim 3)
5. Construct educational resources and decision support tools to enable SDM for PwND (Aim 4)
6. Disseminate results to PwND and all involved in working with and caring for them (Aim 4)

5 STUDY DESIGN

This primary research study will analyse clinical decision-making involving PwND, their carers, and HCPs. It will use Conversation Analysis (CA) to analyse existing (WP1) as well as new cross-sectional (WP2) and longitudinal (WP3) datasets. CA is a qualitative, micro-analytic method for studying real-life interaction widely recognised as the leading methodology for investigating doctor-patient communication in practice [31,32]. Our own previous research has demonstrated how CA-derived insights can be the basis of an online learning resource judged to be capable of changing clinical practice and recommended by NICE [23,46].

In WP 1, we will identify decision points in our existing audio and video recordings of previously transcribed triadic encounters involving patients without cognitive impairment [22]. These recordings were gathered in previous studies in which participants gave consent to use them in future studies. In addition we will draw on previous data from our RfPB study of diagnostic interactions in the memory clinic (including interactions involving participants with memory problems) [4]. Analysing the contributions of third parties in these datasets will allow us to identify differences in the role of the accompanying person when the patient has a neurodegenerative cognitive disorder and will enable us to gain initial insights into the effects of cognitive impairment on triadic decision-making.

In WP2, 100 clinical encounters between patients, carers, and HCP will be video and/or audio recorded in hospital- and community-based specialist memory clinics at both Sheffield Teaching Hospital NHS Foundation Trust, and the Rotherham Doncaster and South Humber NHS Foundation Trust (RDaSH). Apart from the recording of the interaction, our study will have no effect on the content or nature of these encounters. In our analysis of this cross-sectional dataset we will take account of the level of cognitive impairment of the participating patients. We will use the patient’s standard cognitive score on either Addenbrooke’s Cognitive Examination (ACE), Montreal Cognitive Assessment (MoCA) or Mini Mental State (MMSE) findings as a marker of the degree of cognitive impairment. These three tools are the most commonly used as the normal part of these consultations, and participants in WP2 of our study will be stratified on the basis of these scores.

WP3 is the longitudinal arm of the study. In this work package, 10 highly-motivated patient-carer dyads recruited from participants of the cross-sectional study will be involved as co-researchers, helping the research team to record further medical appointments in a range of medical settings (eg., with dementia nurses, occupational therapists, GPs) for the duration of our data collection period (up to two years).

The audio and video data collected in the study will be recorded onto encrypted SD cards, then transferred within 24 hours to secure storage on a University of Sheffield server. The data will be encrypted and shared via Google Drive with a professional transcription service who will decrypt the data, create the transcription, re-encrypt the data and return it through a Google drive folder. All identifying information (eg., proper names) will be anonymised in the transcripts. The video and audio data itself will not be anonymised but will be stored securely on a securely encrypted server at the University of Sheffield, and only members of the research team will have access to the data, unless participants specify otherwise on the consent form.

Participants will be asked to give explicit permission for the audio/video recordings to be used in future research, and for teaching purposes, and to allow short unidentifiable quotes from the transcript to be included in publications. If participants specify that they do not want us to use their data for future research or for training purposes, it will be destroyed after 15 years. Data will then be erased from all computer storage facilities according to the standard university procedures in place at the time for deleting and handling confidential, digital data.

End of the Study

The end of the study will be the last analysis of video or audio recording of an included interaction.

6 STUDY SETTING

WP1 analyses existing data, collected in Sheffield outpatient neurology clinics as part of previous studies. All participants have previously provided consent to use this data in future research and therefore explicit consent for this work package will not be sought.

For WP2, participants will be recruited from referrals to hospital- and community-based specialist memory clinics at both Sheffield Teaching Hospitals NHS Foundation Trust, and the Rotherham Doncaster and South Humber NHS Foundation Trust (RDaSH). These are the only 2 sites involved in the study and the same type of activities are taking place at each site. There are no site specific requirements. Approximately 20 clinicians are involved in consultations across the two memory clinics, and all will be asked for their consent to be recorded.

For WP3, co-researcher participant dyads will be recruited from participants in WP2. They will work with the research team (primarily with the RA) to collect additional video recorded data over a period of two years in a variety of settings including community and primary care, eg., at GP appointments. During the funding application, we were advised by the HRA that this type of longitudinal data collection across a variety of settings was feasible. They stated: “the acute care Trust(s) where patient/carer consent is taken would be classed as a research site [eg., Sheffield Teaching Hospital NHS Foundation Trust, or the Rotherham Doncaster and South Humber NHS Foundation Trust (RDaSH).]. However, the GP practices and tertiary care sites would not be classed as a research site type as there was no requirement to process personal data and all activities would be as per standard of care. Therefore there is no need to inform relevant R&Ds or to gain ‘generic’ consent for sites. However, there is still the expectation that individual clinicians would consent to being recorded. Please note that the clinicians would not count as participants; their consent would purely be for the recording.”

To maximize understanding of and participation in the study, an announcement of the study will be placed in a newsletter sent to Primary Care Sheffield (a GP consortium). Individualised letters will also be sent to the GP practices of the PwND taking part in WP3. Participants will be helped to produce an ‘about me’ card containing study information and contact details which they would introduce themselves to other healthcare professionals. Additionally, the RA will attend appointments with the participant-researchers to answer questions and facilitate recording. The RA will also obtain consent at each appointment before the consultation commences and prior to recording.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

For WP2, only patients who bring a companion/carer with them to their appointment will be eligible. All patients meeting the inclusion criteria will be invited to take part in the study. Some will be follow-up appointments, but some will be attending the memory clinic for the first time. Not all of these new patients will receive a diagnosis of a neurodegenerative cognitive disorder, and if they do not, their data will not be used in this study. Both the patient and their companion/carer must agree to participate or they cannot take part in the study. We will continue recruiting participants until we have recorded 100 consultations with people who already have a diagnosis of neurodegenerative cognitive disorder, or who are diagnosed with a neurodegenerative cognitive disorder as a result of this consultation. Only data from people with a neurodegenerative cognitive disorder diagnosis will be analysed for this study, and only people with a neurodegenerative cognitive disorder diagnosis will be approached for participation in WP3.

Patients who consent to take part in data collection for WP2 will be asked for consent to contact them about future studies. If they consent to this, and if they receive a diagnosis of neurodegenerative cognitive disorder, they will be eligible for WP3, the longitudinal study. Recruitment for WP3 will begin simultaneously with WP2 so we do not expect any difficulty in recruiting 10 dyads in a timely fashion. Therefore the inclusion and exclusion criteria for participants in WP3 are the same as WP2.

7.1.1 Inclusion criteria

- Able to give informed consent
- Two people attending the appointment, in a carer/cared for relationship.
- English speakers, whether as a first or other language.
- Only participants who have already received or are receiving a diagnosis of neurodegenerative cognitive disorder will have their recorded data analysed for this study.

7.1.2 Exclusion criteria

- Unable to give informed consent
- Attending the appointment singly or with someone that is not part of an ongoing caring relationship
- Unable to read/write/understand English

7.2 Sampling

For WP2, we aim to collect 100 consultations (50 per site). The chosen methodology, Conversation Analysis, is an intensive, detail-oriented approach and this number of consultations strikes the appropriate balance between providing enough different interactions and being pragmatic about the time necessary for transcription and analysis of the data. We have allowed for 7 months of data collection at STH and RDASH to ensure we collect enough data to analyse cross-sectionally within the time constraints of the study, and also to simultaneously recruit participants for the longitudinal study (WP3). We will recruit both follow-up and new referrals to the memory clinics, as for new referrals only 60% of the consultations will result in a neurodegenerative cognitive disorders diagnosis. We will include PISs in all memory clinic appointment letters, and consent and record all who indicate an interest in taking part. We will remove the data from the analysis, however, if they are not diagnosed with a neurodegenerative disorder.

For WP3, we will recruit a purposive sample with the aim of achieving maximum variation across categories theoretically predicted to influence shared decision-making (eg., race, age, gender, education level, type of kinship/carer relationship). Race influences HCPs' interactions with patients, and may intersect with other inequities in ways that specifically undermine the capacities of PwND from racialised and otherwise marginalised communities to express their authentic care-related preferences. Supporting shared decision-making for diverse communities will require understanding these intersections, therefore we aim to recruit a sample varying across race, gender, age, education level and type of kinship/carer relationship (this information will have been collected as part of WP2).

We aim to recruit 10 co-researcher participant dyads over a period of up to 2 years. Again, we are taking an approach which balances spread across different environments against time to process and analyse the data alongside the likely changes in capacity of the co-researcher participants. Previous audits suggest that patients will receive 1-3 follow-up appointments per year in the specialist memory services; they are also likely to have appointments elsewhere (e.g. in primary care). Feedback from PPI groups indicated that we should also allow the co-researcher participant pairs to suggest settings they would find beneficial for research, such as home visits from occupational therapy, or even dentist/optometrist appointments, so we are confident of our ability to record numerous encounters with 10 participant pairs.

7.3 Recruitment

WP2: Participants will be people with memory complaints and their care partners attending the memory clinics at the Sheffield Teaching Hospital and RDaSH. Potential participants will receive a short PIS about the study with their appointment letter. The short PIS will contain basic information about the study as well as a phone number, email address and website address to contact for more information. It will also inform them that a member of the research team will be present before their clinic appointment to discuss the study and answer any questions they may have.

When potential participants attend their appointment, receptionists (i.e. members of the clinical care team) will ask patients and companions whether they are interested in taking part in our study, and if they would like to talk to the clinical trial assistant/other member of the research team present in the clinic. This member of the research team would then explain the study again and record people's consent, providing them at this time with the longer PIS. This method of providing information about the study and taking consent was suggested by the PPI co-applicants on this project. They believe that the best way to recruit participants and to make sure they understood the study information was through conversation, rather than written PIS. A full PIS document will be given to the participants once the research team is satisfied that they understand the study, to comply with all necessary legal and ethical guidance

The participants will be informed that taking part in the study will not affect their care or the time it takes to get their diagnosis. They will also be told that they can stop the recording at any time during or at the end of the appointment, and that they can withdraw their data from the study for up to 2 weeks after their consultation and all recordings and data collected as part of the study will be destroyed. After consent is taken, the couple will each be asked to fill out a short form capturing demographic information: DOB, gender, carer relationship (eg., spouses, parent-child) and ethnic group membership.

A recruitment log will be maintained by the local team at each site which will assign each recruited participant a trial ID number. This will be kept separately to the trial data in a secure location on NHS premises (or NHS servers if electronic). Any data collected for the study which can be pseudonymised using this trial ID (e.g. excluding video and audio data) will be stored in a pseudonymised format.

The consultation room will have a video camera set up, which will be switched on by a member of the research team (who will then leave the room) or by the clinician themselves. The consultation will then proceed as normal. During the consultation the clinician will administer the Addenbrooke's Cognitive Examination (ACE), the standard cognitive screening test used in both clinics, and the results of this will be shared with the research team to utilise in the study. Scores on the ACE will be uploaded to a password-protected electronic database stored on the University of Sheffield's servers. This database will contain no participant identifiable data and link the data to participants via their pseudonymised trial ID.

WP3: Participants in WP2 will have indicated on their original consent form whether they consent to be contacted about additional studies. Patients receiving a diagnosis of neurodegenerative memory disorder as identified by one of the consultant neurologists working in the STH memory clinic after their consultation recorded in WP2 will be invited to take part in the longitudinal study. Using information from the demographic survey, we will recruit participants from as diverse a range of PwND and carers as possible, varying across race, gender, and age. Potential participants will be contacted as per their preference to discuss taking part in the longitudinal study. After this conversation, with their permission, they will be sent a written PIS detailing WP3. Within one week, the RA will again contact the pair via their preferred method to answer any questions and take consent. Once we reach a total of 10 co-researcher participant pairs we will stop recruitment.

7.3.1 Consent

Some participants recruited into the study at WP2 will not yet have a diagnosis of neurodegenerative cognitive disorder as we will be recruiting them at their first point of contact with the memory clinics, therefore we have no reason to believe either member of the pair would be lacking capacity. However, recruitment and consent will be carried out by research team members trained in mental capacity assessments, who will be able to assess their ability to make a free choice, to understand the research, and to be capable of making a decision. Participants will receive study introduction flyers (short PIS) before attending their appointment, and at their appointment will be given the chance to ask questions and discuss the study with members of the research team including the clinician they are seeing. Once the research team member doing the consenting is satisfied that they understand the research and wish to take part, they will be provided with written participant information sheets and consent forms which have been co–produced with the PPI co-applicants working in the study team, and approved by the REC.

Participants recruited as part of WP3 will join the study team as co-researcher participants. Members of the research team with specialist training in assessing mental capacity will be in close contact (eg., on a fortnightly or monthly basis) with these participant-researchers. We will ask the member of the participant-research pair who has a neurodegenerative cognitive disorder to agree to continue taking part even if their capacity fluctuates, and if they lose the capacity to consent. This will not be treated as an absolute advance directive, however. We will ask participants to nominate a consultee at the start of the study (who is a different person from the participant-carer). If it is deemed that the PwND at any point no longer has capacity to continue to give consent to participation, we will ask the consultee to act in determining their best interests, keeping in mind that the PwND had previously agreed to continue in the study but balancing this with their ability to communicate or any agitation being caused.

The RA will contact the nominated personal consultees and send them an information sheet about the study and what being a consultee entails. Consultees will have up to 2 weeks to decide whether or not to take on the role, and will be asked to sign a written declaration form.

8 ASSESSMENT AND MANAGEMENT OF RISK

Our sponsor (Sheffield Teaching Hospitals NHS Trust) has advised that they are satisfied that this study is not performing an intervention, nor conducting assessments which offer any potential risk to the participants. Given the nature of neurodegenerative cognitive disorders, the main issue we may face is a loss of capacity to consent to continue taking part. Our procedure for dealing with this is outlined in section 7.3.1 of this protocol.

The study will comply with the Research Governance procedures required by the sponsor, and will be conducted in accordance with the principles of the Declaration of Helsinki.

Transcripts of the recordings will be pseudonymised, with all proper names, places and any other identifiable information replaced. None of the extracts that appear in our publications will allow the identification of individual participants. Additionally, video or audio recordings will only be used for teaching or research purposes if participants have explicitly consented for this.

9 PATIENT & PUBLIC INVOLVEMENT

This project has 4 co-applicant PPI members. They have been/are involved in assessing the acceptability of the research, management of the research, and dissemination of findings. They have provided input on the PIS and consent forms, and meet with the research team on a regular (quarterly) basis to review the study. We also have a member of the public on the Study Steering Committee.

The PPI members were keen that we think beyond adopting the traditional approach to providing lengthy written PIS for prospective participants to read on their own. They suggested that a personal, conversational approach would be the best way of ensuring that potential participants truly understood the research they were being asked to take part in, noting that they themselves have failed to thoroughly read some PIS they have been presented with. Once we explained that we cannot contact potential participants without their consent, they were satisfied that a short PIS introducing the study, sent through the post, followed up by face to face conversation in the memory clinics, would encourage people to take part and ensure that they had a better understanding of the research than being given a written PIS to read and sign, even if they are encouraged to ask questions about it. However we are aware of the legal and ethical importance of providing a written document, and will present this to participants once they have spoken with a member of the research team, shown they understand the research, and indicated their willingness to take part. Both short and long versions of the PIS have been vetted by the PPI members.

10 FUNDING AND INDEMNITY ARRANGEMENTS

The study and its activities will be covered by NHS indemnity. £493,292 of funding has been received to carry out this project from the NIHR Health and Social Care Delivery Research (HSDR) Dementia Call 21/505.

11 DISSEMINATION AND TAKING THE WORK FORWARD

The overall dissemination strategy will be facilitated by the team's close links with professional organisations such as the Royal College of Physicians, Association of British Neurologists, Alzheimer Research UK and General Practice. We have enlisted a study collaborator, Dr Danielle Jones (University of Bradford), who has extensive experience in developing educational materials for clinical and non-clinical health care workers. Her expertise will assist us in building a relationship with Health Education England, to offer summaries of our findings for inclusion in their E-learning modules. The Higher Education Dementia Network (HEDN) launches a new strategy in May, and we will explore this route for dissemination to HEI's, to seek ways to embed our findings within training and education for HCP students on a national level.

Specifically, findings will be disseminated in the following ways:

Dissemination to healthcare professionals and policy makers: the main outputs of the study will be detailed guidance for carers and HCP about (i) how best to facilitate shared decision making and (ii) what pitfalls to avoid. One of the co-investigators chairs the Association of British Neurologists

Specialist Interest Group in Cognitive Impairment and sits on the Dementia Translational research Centre (https://www.nihr.ac.uk/explore-nihr/support/dementia.htm) and thus can share information from this project locally, regionally, and nationally. To ensure that GPs are aware of our work, one of the co-investigators will lead on targeting GPs in Sheffield via their federation (Primary Care Sheffield), in the weekly primary care seminar at the University of Sheffield, via the North regional meeting of the Society of Academic Primary Care (SAPC), the national SAPC annual meeting, and the Royal College of GPs (RCGP). We will work with our local Health Care Partnership in South Yorkshire and Bassetlaw to disseminate within the NHS and care system. Finally, we will host a half-day national workshop to engage with clinicians and policy-makers, review the study results and present the implications and guidelines. The PPI co-applicants will be involved in preparing and delivering this workshop.

Dissemination to academic researchers: the study results will be submitted for publication within peer reviewed health communication and healthcare journals, and presented at appropriate international healthcare and communication conferences. In addition, the study and results will be presented to academic researchers and healthcare professionals through relevant seminars, including the Health Sciences School seminar series at the University of Sheffield, and at the Grand Round for medical members of staff at Sheffield Teaching Hospitals NHS Foundation trust.

*Dissemination to people with dementia and carer*s: in addition to the provision of a full report, technical appendices and executive summary, a lay summary of the study's findings will be prepared with input from the PPI co-applicants and made available in written and short video format to key patient websites and newsletters. We will also seek to present our findings at local dementia advocacy group meetings, eg., quarterly SYDEMRAG meetings. Leaflets summarising the study findings and directing interested parties to further information (eg., charity websites as well as our own self-learning package) will be made available to GPs and other community healthcare settings, including dissemination to existing, marginalised patient groups such as Israac Somali and a South Asian community group that currently collaborate with research team members on another project. Research Champions have been trained from the Israac community group and we have created publicity films and posters to be shared more widely with Israac and other ethnic minority groups. Furthermore, within the workshops we run on what neurodegenerative cognitive disorder is and how it is diagnosed, we will include groups on decision making, as it is particularly important for people from more marginalised groups to understand they have the right to be included. We will also disseminate results through our DeepEnd GP practices which cover parts of Sheffield with higher levels of deprivation (https://www.yorkshiredeependgp.org/).

We will use our findings to develop guidance that will be packaged in the form of two online self-directed learning platforms. Separate platforms will be developed for HCPs and carers. These learning platforms will involve guided analyses of video-samples of successful (appropriately inclusive) and less successful (exclusive) communication strategies for triadic decision making with PwND.

Additionally, we will produce short videos and leaflets that outline the study findings for carers and PwND. These will be designed with the input and oversight of the PPI co-applicants and the participant-researcher dyads to ensure a high level of authenticity and acceptability. Providing both these types of public-facing outputs will ensure maximum outreach regardless of either digital or written literacy, whilst also providing information in forms that are accessible and acceptable to people of all ages. Written information will also be readily translatable for further outreach to non-English speaking communities.

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