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# A family living with Alzheimer's disease: The communicative challenges

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## Abstract

Alzheimer's disease irrevocably challenges a person's capacity to communicate with others. Earlier research on these challenges focused on the language disorders associated with the condition and situated language deficit solely in the limitations of a person's cognitive and semantic impairments. This research falls short of gaining insight into the actual interactional experiences of a person with Alzheimer's and their family. Drawing on a UK data set of 70 telephone calls recorded over a two-and-a-half year period (2006–2008) between one elderly woman affected by Alzheimer's disease, and her daughter and son-in-law, this paper explores the role which communication (and its degeneration) plays in family relationships. Investigating these interactions, using a conversation analytic approach, reveals that there are clearly communicative difficulties, but closer inspection suggests that they arise due to the contingencies that are generated by the other's contributions in the interaction. That being so, this paper marks a departure from the traditional focus on language level analysis and the assumption that deficits are intrinsic to the individual with Alzheimer's, and instead focuses on the collaborative communicative challenges that arise in the interaction itself and which have a profound impact on people's lives and relationships.

## Keywords

Alzheimer's disease, conversation analysis, communication, interaction, collaborative

## Introduction

Alzheimer's disease gradually and irrevocably challenges a person's capacity to communicate with others. Earlier research on these challenges focused on the language disorders associated with the condition, and examined language formation and function impairments. Naming disorders, verbal disfluency, anomia and perseveration errors, as well

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as other semantic impairments were found to be the kind of language deficits symptomatic of Alzheimer's (Bayles & Tomoeda, 1983; Binetti, 1995; Lawson & Barker, 1968). These clinical investigations relied on such methodological techniques as cognitive batteries (Appell, Kertesz, & Fisman, 1982; Bayles, 2003; Blair, Marczinski, Davis-Faroque, & Kertesz, 2007; Fromm & Holland, 1989), picture vocabulary tests (Bayles, 1985; Hier, Hagenlocker, & Shindler, 1985; Shuttleworth & Huber, 1988) and similarity tests (a subset of Wechsler's Adult Intelligence Scale (WAIS) – see Wechsler, 1981; Martin & Fedio, 1983). Despite the congruence between their clinical findings, the methodological validity of such studies has been questioned (Bayles, 2003; Huff, Cokin, & Growden, 1986; Nebes, 1985). Nebes (1985) suggests that language deficits arise from episodic memory failings such as memory or contextual knowledge impairment rather than semantic problems, and suggests that the poor results from tests administered in clinical settings reflect the demands on the person with dementia in these situations. Furthermore, Sabat (1991a) advises that from a profile of tests scores, it would be virtually impossible to infer anything about a person with Alzheimer's communicative and conversational abilities. Sabat proposes that what is being investigated through these methods is how the disease affects a series of 'functions' as opposed to how it affects persons living in the world.

More recent research has investigated the language used by people with Alzheimer's in their discourse in interviews (Aggarwal et al., 2003; Garwick, Detzner, & Boss, 1994; Ripich & Terrell, 1988), narratives (Garcia & Joanette, 1997) and conversations (Mentis, Briggs-Whittaker, & Gramigna, 1995; Orange, Lubinski, & Higginbotham, 1996; Small & Perry, 2005; Spilkin & Bethlehem, 2003; Watson, Chenery, & Carter, 1999). These studies tend to show a range of more pragmatic deficits such as inappropriate topic shifts, abnormalities in appropriate word selection and taking more speaker turns compared with conversations with normal elderly subjects (Campbell-Taylor, 1984; Hutchinson & Jensen, 1980; Ripich & Terrell, 1988). These studies rely on data generated during topic directed interviews or exchanges in artificial clinical situations (Campbell-Taylor, 1984; Ripich & Terrell, 1988). Methods relying on clinical testing and artificial discourse situations treat the language disabilities of the person with dementia in isolation from the social context in which everyday interaction normally takes place, locating deficits solely in their domain. The language problems associated with Alzheimer's have been commonly perceived as a property of the individual, arising from their cognitive dysfunction. It is difficult to extrapolate from research in such artificial situations to the difficulties that a person with Alzheimer's may experience in their natural everyday interactions. Also the deficit-and-patient-focused approach meant that little attention was paid to the other participant and their role in the interaction. Ripich, Vertes, Whitehouse, Fulton, and Ekelman (1991, p.332) reported that, 'although the literature reveals little information regarding discourse of Alzheimer's patients, even less is reported about the discourse of their partners. Knowledge of partner's discourse features is crucial since communication is reciprocal with each participant shaping the interaction'. Along with this focus on interaction, there was increasingly a shift in perspective, away from communicative disorder as solely situated in the limitations of a person's communicative impairments, towards a wider focus on communication as a joint, collaborative achievement. It is fundamental to perceive any impairment in communicative functioning or general patterns and features of interaction as contextually situated and collaboratively produced (Hamilton, 1994; Jones, 2012; Perkins, Whitworth, & Lesser, 1998; Sabat, 1991b).

There is a greater concern in conversation analytic (CA) research to address the notion of communicative ability as a contingent and emergent phenomenon in the field of dementia research (Guendouzi & Muller, 2006; Hamilton, 1994; Mikesell, 2009, 2010; Perkins et al., 1998; Wilson, Muller, & Damico, 2007). There is already an established body of CA research in the field of cognitive impairment, such as autism (Local & Wootton, 1995; Stribling, Rae, & Dickerson, 2009) and traumatic brain injury (Body, 2007; Body & Parker, 2005) as well as language impairments such as aphasia (Goodwin, 2003; Goodwin, Goodwin, & Olsher, 2002; Wilkinson, 1999; Wilkinson, Beeke, & Maxim, 2010) and intellectual disabilities (Williams, 2011), in studies of the sequential nature of collaborative and naturally occurring interaction. However, the CA literature on interaction and Alzheimer's is still very young, with a focus on other dementias, for example frontotemporal dementia (Mates, Mikesell, & Smith, 2010; Mikesell, 2009), as well as Alzheimer's disease (Hamilton, 1994; Jones, 2006; Wilson et al., 2007). Rather than studying single utterances and isolated language products, CA researchers focus on 'uncovering the *socially organized features of talk in context*, with a major focus on actions sequences' (Heritage & Atkinson, 1984, p.5). Some of the focal points of CA investigations have been repair (Watson et al., 1999), laughter (Wilson et al., 2007) and questions (Hamilton, 1994; Jones, 2006; Mikesell, 2009). These studies, and indeed my own research (Jones, 2012) has found that, in the presence of a progressive cognitive deficit, persons with dementia often retain the social proficiency that permits them to contribute to conversation as a social action in meaningful and contextually appropriate ways and are competent and cooperative conversationalists (Hamilton, 1994; Jones, 2012; Muller & Wilson, 2008; Sabat, 1991b).

One of the fundamental challenges for communication previously unexplored in this literature lies not in the semantic domain or with certain practices of talk, for example whether a person with Alzheimer's can perform a repair operation or if they can accurately respond to or ask questions, but instead lies at the heart of one of the most detrimental consequences of the disease: episodic memory impairment. Memory loss is one of the most prominent and distressing cognitive disturbances associated with Alzheimer's disease. Episodic memory impairments can often impede an individual's ability to retrieve a previous experience and hinder the knowledge they can retain about the world generally, and indeed about themselves and their lives. As the disease progresses, a person's ability to identify themselves, what they are doing and who the people are around them decreases (Kennard, 2009). Often one's memory regresses to a stage where an individual believes they are living in the past. As a corollary of these memory impairments there often appears to be misalignment between participants in interaction. The person with dementia may be trying to interpret a world that no longer makes sense to them whilst those around them often do not understand or account for this in their communication. The co-participant in any given conversation will often use 'ordinary' interactional practices that are straightforward in their everyday interaction, but that are inapposite when conversing with someone with memory impairments. This misalignment of intersubjectivity, or shared understandings between interlocutors, has profound implications for interaction and lies at the heart of the communicative challenges faced by people with Alzheimer's disease and their family. Investigating these interactions reveals that there are clearly communicative difficulties, but closer inspection suggests that they arise due to the contingencies generated by the other's contributions in the interaction. That being so, this paper marks a departure from the traditional focus on language level analysis and the assumption that deficits are intrinsic to the individual with Alzheimer's. Instead it focuses

on the collaborative communicative challenges that arise in ordinary interactions in which people with Alzheimer's take part – challenges that have a profound impact on people's lives and relationships.

## Data and methods

The data were collected as part of the author's PhD research and consist of audio recordings of 70 naturally occurring telephone conversations between a woman with Alzheimer's (pseudonymised as 'May') and her family members (daughter 'Natalie' and son-in-law 'Bill'), recorded between February 2006 and June 2008. The recorded conversations range from 23 s to 8 min and 30 s (average duration 1.68 min). A recording device was attached to the family's telephone. The device was manually operated, recording May's calls only. The family inspected the calls before giving them to the researcher for analysis to ensure they could delete any recordings they did not want to feature in the research. In 2006, when recording began, May was 72 years old and had been diagnosed with Alzheimer's 5 years previously. May was resident at 'Lilly Hill', a residential home for the elderly; towards the end of the study she moved to 'Searle Court', a specialist care home for people living with dementia. During the period of study May displayed symptoms associated with moderate stage Alzheimer's, including confusion over her surroundings, needing substantial support in daily living (for example dressing/cooking), being forgetful and anxious. Towards the end of the study, May was reaching the stage of severe cognitive decline, although retaining a good standard of semantic functioning. The most noticeable change was the degeneration of her episodic memory.

Ethical permission for the study was sought as part of the researcher's PhD proposal and the ethics panel at the researcher's University approved the proposal before research was conducted. The significance of thorough ethical considerations is particularly pertinent in research involving vulnerable adults. The BSA (sections 16 and 29) code states, "As far as possible participation in sociological research should be based on the freely given informed consent of those studied". Furthermore, "Special care should be taken where research participants are particularly vulnerable by virtue of factors such as age, disability, their physical or mental health...where there are particular difficulties in eliciting fully informed consent. In some situations proxies may need to be used in order to gather data. Where proxies are used, care should be taken not to intrude on the personal space of the person to whom the data ultimately refer, or to disturb the relationship between this person and the proxy". In accordance with these regulations, and after consideration of the ethical complexities, informed consent was obtained from all the participants prior to collecting the data: consent was given on behalf of the person with Alzheimer's by her daughter. It was deemed (by her daughter, working in May's best interest) reasonably practicable not to consult May directly about her participation in the research. As a researcher, I was mindful not to impose a burden on the participants or cause ill effect. This research presents a dilemma caused by the conflict between research involving participants who are incapable of giving informed consent, weighted against the benefits of that research for informing dementia care. The interests of the participants were always considered above those of the study. The Mental Capacity Act 2005 provided continued guidance for the research.

The recordings were transcribed in considerable detail, to capture particular aspects of the timing of speech (e.g. overlapping speech, pauses within and between speakers' turns), and

how things are said (including certain international features, emphasis, stretching of sounds and words), using the transcriptions conventions widely adopted in CA (Jefferson, 1983, 2004; for transcription conventions see Appendix 1). In transcribing the data, all names of people, places and other potentially identifying information have been pseudonymised. Recordings of real-life interactions are used because people's recall is often incomplete or faulty and repeated viewing of conversations enables us to capture and investigate micro-details (e.g. silences, pitch, emphasis, self-repairs) that go beyond anyone's ability to recall.

CA was used as a method for analysing the data (for a summary see Drew, 2005; Sidnell, 2010). CA aims to explicate the practices through which interactants accomplish social actions and understand one another's conduct in conversation. CA is concerned with the analysis of talk-in-interaction, which is a highly organised and orderly turn-taking system, in which interactants design their talk within a sequential context to fulfill certain tasks. Turn design is a fundamental property of all interactions and 'refers to how a speaker constructs a turn-at-talk' (Drew, 2013, p.132). Our talk is designed with respect to certain contingencies, to where in a sequence of talk a turn is being taken, to what is being done in that turn (i.e. what action we are trying to accomplish) and to whom the turn is addressed. Thus, a turn at talk is contingent on the other in interaction – their conduct, knowledge and competence. Taking into consideration what you take your recipient to know, or progressively not know – recipient design, lies at the very heart of turn design (Drew, 2013; Goodwin, 1979) and has implications on how interaction progresses. This study addresses the notion of the appropriateness of a turn's design relative to who is being addressed and more specifically examines how turn design can have significant influence on achieving good communication between a woman with Alzheimer's and her family members.

The paper will present only a small number of extracts, comprising only short communicative exchanges, but they exemplify larger patterns in the data (not statistically presented here). Where appropriate, data extracts from ordinary interaction (widely used in the CA community – extracts 1 and 4) will be used to offer a comparison to the patterns of interaction found between May and her family. This is a practice routinely used in CA research to provide evidence for the findings.

## Analysis

### You rang?

Questions are omnirelevant in ordinary interaction. A key feature is that they generally rely on or presuppose a recipient's memory. Questions do not need to be grammatically interrogative – they can be declaratively formed, e.g. 'You Rang?', nonetheless they imply an imbalance of knowledge between speakers. Questions are designed to address this imbalance (see Heritage & Roth, 1995; Stivers, Mondada, & Steensig, 2011). Before illustrating these points with data from May's interactions, I demonstrate briefly how episodic memory can successfully be presupposed in the design of speakers' turns during 'ordinary' interaction. In the following extract a daughter ('Jess') returns a missed call from her father ('Bill'). There are a specific range of contingences associated with the initiation of business in call-backs which are often managed by the introduction of a particular interactional resource – "you rang" (or its variants).[1] Asking a co-participant if they had previously called requires the recipient not only to remember whether they did indeed call,

but also what they called about, and to initiate this business. In extract one, these interactional tasks run off smoothly.

    Extract 1
    DJ: JB03
    01 BIL: Hello:,
    02 (0.2)
    03 JES: Hi:::, Did you ri:ng me¿
    04 (0.6)
    05 BIL: Yea::h. Just picked up on that ne:w:s.

Jess reasonably and successfully presupposes Bill's memory of previously calling her when designing her turn 'Did you ring me'. It is reasonable and successful as Bill continues to confirm that he did call and proceeds to the business. Although not an explicit topic initiator (as the topic is not directly stated but only referred to as 'news'), this orients to establishing a topic which is 'known-in-common' and newsworthy and which has previously been alluded to or talked about. This exchange relies on both parties having intact episodic memory. Employing such resources, which requires both the recollection and explication of some prior event, is a potentially problematic practice in talk-in-interaction when a person's episodic memory is failing. Compare this with May's management of the same interactional task.

    Extract 2
    ALZ45
    01 MAY: Hello:,
    02 NAT: Hello:,
    03 (0.3)
    04 NAT: You tried to ring me I think a minute ago:.
    05 (0.6)
    06 MAY: Did I:,
    07 (0.6)
    08 MAY: Oh honestly. I'm sorry Natalie.
    09 (0.4)
    10 NAT: >Well it doesn't matter,<
    11 (0.4)
    12 NAT: Do you know what you wanted. ↑No,
    13 (0.8)

In part, the troubles May and her family experience at the start of many of their conversations result from May's inability to operate the care home's payphone. The payphone operates by the user dialing the number, listening for a connection, and then, when a recipient answers, inserting the coins. As the large number of failed attempts and call-backs on tape bear witness, May found this process challenging and often either did not have the correct money to connect the call or could not insert the coins before the connection failed.[2] May's family would then call her back, usually within seconds of her initial attempt. Due to the proximate nature of these calls, one might expect May to remember that she just tried calling her family and what it was she called about. Indeed by using the declarative version of "did you ring me" (in extract 1 in it is interrogative form) – "you tried to ring me I think a minute ago" (line 4) her family is displaying this expectation in the interaction itself (albeit slightly mitigated with the inclusion of "I think"). Despite the proximate occurrence

of these returned calls in relation to the initial attempt, and due to the severity of her cognitive deficits, May often displays no recollection of a call taking place, or indeed what it was she wanted – here she asks, "did I". May and her daughter come to experience difficulty in the interaction when Natalie presupposes May's episodic memory in the design of her turn but May is not able to recall that particular memory when responding. Natalie does not take into consideration what her recipient progressively does not know when designing her turn at talk that subsequently generates troubles in the unfolding interaction.

Despite such troubles that are collaboratively generated in the interaction, May is often able to show herself to be as a competent conversationalist by demonstrating that she understands the requirements of the interaction but, due to her cognitive deficit, is not able to meet the demands of that particular communicative resource which is initiated by the other.

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Extract 3
ALZ08
01 ((Dialling))
02 ((Ring, Ring-Ring))
03 (2.2)
04 ((Clunking sound))
05 MAY: Hello::,
06 NAT: Hello.=You ra:ng. hh[h]
07 MAY: [O]h sorry love. Ye:s.
08 (1.2)
09 MAY: Am I coming tomorro:w.
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May routinely manages these difficult interactional moments by reverting to her 'default' reason for calling – her return home (business that she initiates in various ways in 42 of the 70 calls). Whether this enquiry – "Am I coming tomorrow" (line 09) is initiated in the absence of her recollecting another topic (the topic that she 'actually' wanted to discuss) or whether this was her original business is somewhat uncertain here. However, she displays some troubles with remembering. Although she does produce the required confirmation – 'Yes' (line 7), which is aided by the certainty encompassed in the declarative construction of "you rang", there is nevertheless a lengthy gap before the production of this default business, which is indicative of troubles. Furthermore the turn-initial 'oh' preface to the apology is indicative of some problem with Natalie's prior and marks May's acknowledgement of new information (Heritage, 1984). Although May is displaying some interactional competence she is evidently struggling with this exchange due to the relevancies mobilised by the introduction of 'you rang', which presents a challenge to her episodic memory capabilities. Asking a person with little or no short-term memory to recount their recent actions is a risky move. Here Natalie has designed her turn using an ordinary interactional resource to presuppose episodic memory, which fails to take into account May's cognitive capabilities, thus generating difficulties in the communication.

## Other questions

There are other question types that are designed to presuppose episodic memory (about the kind of day May has had and what she has done) that May's family often employ to distract

her from the problems encountered at the start of the calls, which unexpectedly generate
further problems in the interaction. Again, before illustrating these with data from May's
interactions, I demonstrate briefly how episodic memory is routinely and successfully
presupposed in the design of speakers' questions during 'ordinary' interaction. In the
following Lesley asks her Mum if she has been to Church. The ability to respond
relevantly to this question relies on the recipient's intact episodic memory. In extract 4,
this interactional task runs off smoothly.

> Extract 4
> Field: September-October 1988 (II): Side 2: Call 8
> 01 Les:.pt.h Have you been t'Chu↑:rch?
> 02 Mum: Yes. (0.2) [We've been i[n a few minutes but (.) I've]=
> 03(Ski): ([[) ((whispered))]=
> 04 [((clattering noises]=
> 05 Mum: =[been watching Howard's Wa:y,

Mum is able to recall her attendance at Church and produce the required response – a
confirmatory unmarked interjection – 'Yes' (line 02). Now compare this with May's
responses to similar interactional task.

> Extract 5
> ALZ08
> 01 NAT:.hh That's alright.=↑Did you go to
> 02 Church this morning, hh
> 03 (0.3)
> 04 MAY: I haven't a clue darling.

> Extract 6
> ALZ37
> 01 NAT: Did you have a nice lunch ou:t.
> 02 (0.6)
> 03 ((Door knocks))
> 04 MAY: I'm sorry Natalie I can't remember anything
> 05 these da:ys.

It is evident that May is unable to recollect her attendance at Church that morning and
whether she had a nice lunch out. Her episodic memory deficit prohibits her from engaging
competently in these interactions. She is unable to produce the simple confirmatory
interjections that are made relevant by the questions (as was seen in the previous extract).
Instead her avowal of forgetting is open and extreme (not being able to remember
"anything" and not having a "clue"; Pomerantz, 1986). Again her co-participant is
presupposing episodic memory in the design of the questions but May is unable to recall
the particular memories on which to base her responses. The misalignment here is not
generated because of May's cognitive deficits alone. Instead the misalignment is
interactionally generated by questions that are in some way 'ill fitted' to May's cognitive
competences. In May's case, her episodic memory deficits have become so grave that
questions designed to place her in a position of primacy and therefore make her
responsible for recounting information (about whether she went to Church or had a nice
lunch) have the unintended consequence of exposing her lack of knowledge. Such questions

introduce a whole new set of challenges for May, which cause both interactional and social friction between her and her family members.

Again, despite these troubles that are collaboratively generated in the interaction, May is often able to display herself to be a competent conversationalist by initiating sophisticated interactional tasks to establish the 'correct' response to the questions (based not from her memory per se but from information she obtains in the interaction).

Extract 7
ALZ01
01 NAT: Mother don't worry about it.>Tell me did you
02 go to church this morning,
03 (3.2)
04 MAY: I think I did. Ye:s.
05 (0.6)
06 MAY: It is Sunda:y.
07 NAT: It's Sunda:y. Yes.
08 (0.3)
09 NAT: I think maybe the Brears came to get
10 you.=[Did they,]
11 MAY: [They di]d Natalie. You're quite
12 right. I'm sorry.

Natalie's question, "Did you go to Church this morning" is not only designed to presuppose May's episodic memory capabilities but that she is able to remember and tell Natalie what she wants to know. This question generates difficulty for May, as the long delay in answering and the uncertain response itself "I think I did. Yes" (line 04) are indicative of May's inability to recall her attendance at Church. However, May competently demonstrates her awareness that 'Yes' is the interactionally appropriate response. She also displays competence in managing the difficulties posed by the question by eliciting further information from which she can base a more certain response. By asking "Is it Sunday" May proficiently retrieves 'Sunday' from the mention of 'church' and 'this morning' and attempts to establish whether this is a valid question (i.e. that Natalie is not trying to catch her out), whether it would be a likely practice for her, and thus enable her to confirm that she attended. After information from Natalie about May's morning, May confirms that the information is correct but does not directly answer the initial question. Although her turn begins with a strong claim to remember the Brears 'getting her', May is not making a claim to having the knowledge of her attendance at Church. Despite some of May's interactional accomplishments during this sequence, she is unable to evoke the memory of the event, which she needs in order to engage successfully with the question asked by the other. Misalignment is generated by a question that is designed for someone whose episodic memory is functional.

It is difficult to make the claim that May 'answers without knowing'. That being, it is difficult to say that May does not remember the events taking place but is able to rely on her interactional skills to 'come up' with the correct response. Making claims about May's actual memory is dubious. However, these claims become more acceptable when May's answers backfire – when May's answers (that claim memory) turn out to be incorrect. In the extract below, like all the others, Natalie's initial question is designed to presuppose May's episodic memory of the type of day she has had. May's claim to remember

doing 'nothing special' backfires when it turns out she has had a 'special' day (Laura and Jack, May's other daughter and son-in-law have visited) – she shows she is 'answering without knowing'.

> Extract 8
> ALZ61
> 01 NAT: Have you had a nice da:y,
> 02 (0.2)
> 03 MAY: I think so dear.= Well (.) the usual sort
> 04 of da:y. Nothing special.
> 05 NAT: Well I thought Laura and Jack came toda:y,
> 06 (0.8)
> 07 MAY: Sorry?
> 08 NAT: I thought you'd been out with Laura and
> 09 Jack toda:y,
> 10 (1.0)
> 11 MAY: Oh blimey. What day is it today.
> 12 NAT:.hhh Well today is Good Friday but I
> 13 think you di:d.
> 14 MAY: Sorry?
> 15 NAT:.h Today is Good Friday.
> 16 (2.4)
> 17 MAY: Ri:ght. Well if I- if you say I have
> 18 I have darling and thoroughly enjoyed
> 19 it.
> 20 NAT:.hh Good. That's alright then.

'Answering without knowing' is a tactic or technique May has developed and employs to display herself as being a competent interactant (this may be akin to the techniques that people with other conditions such as Tourette's or Aspergers develop to 'pass for normal' Wilensky, 2000). Indeed by doing this May is demonstrating her communicative competence in the absence of cognitive capability. However, when she gets it wrong it exposes her cognitive impairments that she is working hard to disguise. These difficult interactional moments arise due to the contingencies that are generated by the other's contributions in the interaction – due to the turns-at-talk they take which are designed without the recipient's capabilities and impairments in mind.

## Responding to May's questions

The difficulties that arise in these interactions are not only generated by the other's questions, but their responses to May's questions. During these conversations misalignment appears between the knowledge May has about her own life, and the knowledge her family have about May's life. This misalignment causes interactional as well as social friction. The telephone conversations are overwhelmingly driven by May's desire to return home. One consequence of her Alzheimer's is that, despite having lived in the residential facility for some eight months before recording began, May discovers on a daily basis, always with shock, as if for the first time, that she is no longer living in her own home. People with Alzheimer's often do not recognise their current environment as 'home' and therefore repeatedly ask to return 'home' to a place there they felt comfortable and safe.

May repeatedly calls her family to make a request to return home, which is subsequently and repeatedly denied, causing anxiety and distress.

    Extract 9
    ALZ59
    01 MAY: I'm coming home tomorrow aren't I:,
    02 (0.8)
    03 BIL: ER:: No::,
    04 (0.4)
    05 MAY: Oh Bi:ll.
    06 (1.2)
    07 MAY: I thought I was- (0.4) only here for a
    08 short time:.
    Extract 10
    ALZ49
    01 MAY: When am I coming home.
    02 (0.4)
    03 NAT: Well you're not coming home 'cause that's where
    04 you live no:w.
    05 MAY: Bloody Hell. I cannot accept tha:t. I really can't.
    Extract 11
    ALZ10
    01 MAY: When am I coming home.
    02 NAT:.hh(.) Wul you're not coming home any time soon
    03 Mother 'cause that's that's where you're living
    04 just now.
    05 MAY: Oh bloody hell. I keep forgetting tha:t I know.

May designs her questioning turns (9:01, 10:01 and 11:01) to embody a clear assumption – that she is returning home, the only issue being when. This makes declining these requests somewhat harder for her family as May is displaying a specific orientation to the unproblematic nature of the request being granted. However, the requests are always denied. Her family often bluntly informs her that the care home is now her home. Not only do these responses decline to grant May's request to return home, they also directly contradict her assumption and expose her memory loss. The misalignment and consequent trouble (the shock and distress May experiences) is generated collaboratively in the sequence by the inapposite questions posed by May (asked because to her lack of memory about her living arrangements) as well as the contradictory response given by her family (which do not support May's knowledge of her life).

May also designs her questioning turns using modal verbs – "can I" which reflects her entitlement to make the request and the unproblematic contingencies associated with her family granting it (see Curl & Drew, 2008 for an explanation of such requests). Despite this construction, her family nevertheless continues to contradict this sense of entitlement and decline her return home.

    Extract 12
    ALZ20
    01 MAY: Well when can I come ho:me.
    02 BIL: Oh nhuh huh.hhh I don't kno::w you- well-

03 (0.6)
04 MAY: I'm sorry am I a great problem Bill.
05 (.)
06 BIL:.hh er:m (.) well not a great problem
07 no::..h but you do know that you're living
08 there now don't ya.

May still appears interactionally quite perceptive, in recognising Bill's evasive and indirect response (line 02) as indicative of her being a 'problem' in some way. However, her cognitive impairment, which affects her ability to remember important information about her life, like where she is living, poses difficulties in interaction for her family. The significance of all these requests is that, for May, they are the first time she is asking to return home (as she has forgotten any previous request). The problems occurred when May's recipients do not match their responses to fit the assumptions embodied in the requests, often quite uncompromisingly declining them, for the hundredth time. There is misalignment between 'first time' request and 'nth time' response. The responses also do not reflect May's 'reality' (that she will return home soon), which causes problems.

There are two distinct approaches to caring for people with dementia – to collaborate with their 'reality' (telling May, for instance, that she will return home soon) or to contradict that 'reality' if it does not fit with the events of the 'here and now' (telling May that she is not returning home because she resides in the care facility). The morality, legality and ethicality of 'deception' in dementia care are widely debated topics (Day, James, Meyer, & Lee, 2011; Elvish, James, & Milne, 2010; Hasselkus, 1997; James, 2008; Marzanski, 2000; Schermer, 2007; Tuckett, 2011; Wood-Mitchell, Waterworth, Stephenson, & James, 2006). Although I will not explore these arguments here it is important to note that in May's case, the 'truth' exposes her episodic memory impairments as it contradicts her knowledge about her life and causes her great shock and distress.

## Discussion

It is clear that Alzheimer's disease irrevocably challenges a person's capacity to communicate with others. The previous research literature has tended to focus on the language disorders associated with the condition, which are taken to have a cognitive basis. This diminishing capacity to communicate however is not solely situated in the limitations of a person's cognitive and semantic impairments that have been the focus of previous research testing. The real communicative difficulties people with Alzheimer's experience are interactional – they may arise, in part, from their cognitive deficits (especially their failing episodic memory) but challenges are occasioned by, or are contingent on, the other's contributions in interaction. Such contributions we take for granted in our everyday interactions – presupposing that the recipient to a question will be able to answer it. These questions are omnirelevant and the presuppositions embedded in the design of them always rely on a recipient's memory. Communication challenges are thrown up in interactions between May and her family when questions designed to presuppose memory are unsuccessful (and May is unable to recall the answer), and indeed when May's presuppositions about her life are exposed as being incorrect by her family's contradictory responses to her questions. It is important to note that the family's contribution in these interactions is not designed deliberately to expose May's deficit. Family members often have a difficult task to maintain positive communication and often questions asked in these interactions were an

attempt to overcome some of the other difficulties experienced during the start of the calls. It is useful to realise when practices in interaction have the unintended consequence of generating troubles so that we can work to overcome these problems in subsequent communication.

What I have shown is a brief overview of a small number of these interactional co-constructed communicative problems. They are part of a wider investigation of the difficulties people with Alzheimer's experience in interacting with others. This paper has marked a departure from the traditional focus on language level analysis and the assumption that communicative deficits are intrinsic to the individual with Alzheimer's, and instead focuses on the collaborative communicative challenges that arise in the interaction itself.

What is especially interesting about these complex and problematic interactional moments is a person with Alzheimer's ability to develop strategies for coping in interaction, for displaying interactional competence despite their cognitive deficits. Although these strategies are not always successful, May has nevertheless developed a technique of 'answer without knowing' as a tactic for 'passing for normal' to disguise her cognitive troubles. In doing so she is demonstrating her communicative competence in the absence of cognitive capability.

The significance of understanding communication as collaborative, and problems in interaction as co-constructed, is that family members can play an active part in co-managing interactions with their relatives who have Alzheimer's in the hope that conversations will be more rewarding for those involved, and that important relationships can be maintained for longer.

## Limitations: A consideration of a single case

Analysis was based on only a single person – although the findings resonate with research involving other people with Alzheimer's in a range of environments, which points to the likely conceptual transferability of findings, there are limitations regarding representation and generalisability.

This research is not necessarily representative of people with Alzheimer's and their experiences in general. There is great variability in the communicative impairments experienced by people with Alzheimer's, compounded by the heterogeneous nature of the disease more generally; assessing only one person does not represent this variation. One person may present with particular and unique symptoms, may have a distinctive communication style or may be influenced by their specific social and cultural circumstances. These variables, as well as the type of dementia a person has, may significantly alter their interactions and the subsequent analyses of them. Although certain symptoms and behaviours can appear in people with Alzheimer's at the same stage, it is important to acknowledge the caveat that the findings may not apply to everyone with the disease, thereby limiting the generalisability of the results reported here. Nevertheless there has been an increasing acceptance of the use of single case studies in dementia research (Freeman, 2008; Hamilton, 1994, 2008; Muller & Guendouzi, 2002, 2005; Muller & Wilson, 2008; Ramanathan, 1994). A number of these researchers pointed out the complexities inherent in the group studies of people with Alzheimer's due to the variability in the nature of their communicative impairments (Bayles, 1985; Gardner, 1974) and the heterogeneous nature of the disease more generally (Ritchie & Touchon,

1992; Schellenberg, 1995). They advocated adopting an in-depth individualistic approach to the examination of language. Therefore, the methodological emphasis and strength resides in its 'rigorous analysis of small numbers of sequences' (Wootton, 1997: p.ix), with the available recordings creating a special opportunity for the extensive exploration of interaction. Whilst the specific findings regarding May and her family's communication may not apply directly to other interactions between other conversational partners, nevertheless "an in-depth examination of language used by particular people in particular interactions will provide us with a heightened understanding of interactional influence on language as it relates to Alzheimer's disease" (Hamilton, 1994: p.31).

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None declared.

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## Notes

1. This is worthy of closer analytic attention and will be the subject of a future paper.
2. This is an ongoing trouble for many people who have Alzheimer's who reside in care as homes routinely provide their residents with pay phones. Also family members often prefer this mode of communication as opposed to using mobile phones. When discussing these issues with Natalie I suggested that the problems May experiences with the payphone causes great interactional difficulties at the beginnings of all the calls. I suggested providing May with a mobile phone with restricted credit. Her family thought this would be an unwise solution as May would call at all hour of the day and night. The staff at the home can at least regulate the payphone during the night whereas mobile use would not be regulated.

## References

Aggarwal, N., Vass, A. A., Minardi, H. A., Ward, R., Garfield, C., & Cybyk, B. (2003). People with dementia and their relatives: Personal experiences of Alzheimer's and of the provision of care. *Journal of Psychiatric and Mental Health Nursing*, *10*, 187–197.

Appell, J., Kertesz, A., & Fisman, M. (1982). A study of language functioning in Alzheimer patients. *Brain and Language*, *17*, 73–91.

Bayles, K. A. (1985). Communication in dementia. In H. Ulatowska (Ed.), *The aging brain* (pp. 157–173). San Diego: College-Hill Press.

Bayles, K. A. (2003). Effects of working memory deficits on the communicative functioning of Alzheimer's dementia patients. *Journal of Communication Disorders*, *36*, 209–219.

Bayles, K. A., & Tomoeda, C. K. (1983). Confrontation naming impairment in dementia. *Brian & Language*, *19*, 98–117.

Binetti, G. (1995). Semantic memory in Alzheimer's disease: An analysis of category fluency. *Journal of Clinical and Experimental Neuropsychology*, *17*, 82–89.

Blair, M., Marczinski, C. A., Davis-Faroque, N., & Kertesz, A. (2007). A longitudinal study of language decline in Alzheimer's disease and frontotemporal dementia. *Journal of the International Neuropsychological Society*, *13*, 237–245.

Body, R. (2007). Decision making and somantic markers in conversation after traumatic brain injury. *Aphasiology*, *21*, 394–408.

Body, R., & Parker, M. (2005). Topic repetitiveness after traumatic brain injury: an emergent, jointly managed behaviour. *Clinical Linguistics and Phonetics*, *19*, 379–392.

Bond, J., & Corner, L. (2001). Researching dementia: are there unique methodological challenges for health services research? *Ageing & Society*, *21*, 95–116.

Campbell-Taylor, I. (1984). *Dimensions of clinical judgement in the diagnosis of Alzheimer's disease*. Unpublished PhD dissertation, University of New York, Buffalo, NY.

Curl, T., & Drew, P. (2008). Contingency and action: a comparison of two forms of requesting. *Research on Language and Social Interaction*, *41*, 1–15.

Day, A. M., James, I. A., Meyer, T. D., & Lee, D. R. (2011). Do people with dementia find lies and deception in dementia care acceptable. *Aging & Mental Health*, *15*, 822–829.

Drew, P. (2005). Conversation analysis. In K. L. Fitch, & R. E. Sanders (Eds.), *Handbook of language and social interaction* (pp. 71–102). London, UK: Lawrence Erlbaum Associates Publishers.

Drew, P. (2013). Turn design. In J. Sidnell, & T. Stivers (Eds.), *Handbook of conversation analysis* (pp. 131–149). Sussex, UK: Blackwell-Wiley.

Elvish, R., James, I., & Milne, D. (2010). Lying in dementia care: An example of a culture that deceives in people's best interests. *Aging & Mental Health*, *14*, 255–262.

Freeman, M. (2008). Beyond narrative: dementia's tragic promise. In L. Hyden, & J. Brockmeier (Eds.), *Health, illness and culture* (pp. 169–185). London, UK: Routledge.

Fromm, D., & Holland, A. L. (1989). Functional communication in Alzheimer's disease. *Journal of Speech, Language and Hearing Research*, *54*, 535–540.

Garcia, L. J., & Joanette, Y. (1997). Analysis of conversational topic shifts: A multiple case study. *Brain and Language*, *58*, 92–114.

Gardner, H. (1974). *The shattered mind: the person after brain damage*. New York, NY: Random House.

Garwick, A. W., Detzner, D., & Boss, P. (1994). Family perceptions of living with Alzheimer's disease. *Family Process*, *33*, 327–340.

Goodwin, C. (1979). The interactive construction of a sentence in natural conversation. In G. Psathas (Ed.), *Everyday language: Studies in ethnomethodology* (pp. 97–121). New York, NY: Irvington Publishers.

Goodwin, C. (2003). Conversational frameworks for the accomplishment of meaning in aphasia. In C. Goodwin (Ed.), *Conversation and brain damage* (pp. 90–116). New York, NY: Oxford University Press.

Goodwin, C., Goodwin, M. H., & Olsher, D. (2002). Producing sense with nonsense syllables: Turn and sequence in the conversation of a man with severe aphasia. In B. Fox, C. Ford, & S. Thompson (Eds.), *Language of turn and sequence* (pp. 56–80). Oxford, UK: University Press.

Guendouzi, J. A., & Muller, N. (2006). *Approaches to discourse in dementia*. Mahwah: Lawrence Erlbaum Associates.

Hamilton, H. E. (1994). *Conversations with an Alzheimer's patient: An interactional sociolinguistic study*. Cambridge, UK: Cambridge University Press.

Hamilton, H. E. (2008). Language and dementia: sociolinguistic aspects. *Annual Review of Applied Linguistics*, *28*, 91–110.

Hasselkus, B. R. (1997). Everyday ethics in dementia care: narrative of crossing the line. *Gerontologist*, *37*, 640–649.

Heritage, J. (1984). A change-of-state token and aspects of its sequential placement. In J. M. Atkinson, & J. Heritage (Eds.), *Structures of social action: Studies in conversation analysis* (pp. 299–345). Cambridge, UK: Cambridge University Press.

Heritage, J., & Atkinson, J. M. (1984). Introduction. In J. M. Atkinson, & J. Heritage (Eds.), *Structures of social action: Studies in conversation analysis* (pp. 1–16). Cambridge, UK: Cambridge University Press.

Heritage, J., & Roth, A. (1995). Grammar and institution: questions and questioning in the broadcast news interview. *Research on Language and Social Interaction*, *28*, 1–60.

Hier, D. B., Hagenlocker, K., & Shindler, A. G. (1985). Language disintegration in dementia: Effects of etiology and severity. *Brain and Language*, *25*, 117–133.

Huff, F. J., Cokin, S., & Growden, J. H. (1986). Semantic impairment and anomia in Alzheimer's disease. *Brain and Language*, *28*, 235–249.

Hutchinson, J. M., & Jensen, M. (1980). A pragmatic evaluation of discourse communication in normal and senile elderly in a nursing home. In L. K. Obler & M. L. Albert (Eds.), *Language and communication in the elderly*. New York, NY: D.C. Heath & Company.

James, O. (2008). *Contented dementia: 24-hour wraparound care for lifelong well-being*. London, UK: Vermilion Random House.

Jefferson, G. (1983). Issues in the transcription of naturally-occurring talk: Caricature versus capturing pronunciational particulars. *Tilburg papers in language and literature*, Tilburg University, Tilburg. pp. 1–12.

Jefferson, G. (2004). Glossary of transcript symbols with an introduction. In G. H. Lerner (Ed.), *Conversation analysis: Studies from the first generation* (pp. 13–23). Philadelphia: John Benjamins.

Jones, D. (2006). Please can I come home: conversations with an Alzheimer's patient. BA (Hons) dissertation, Department of Sociology, University of York, UK.

Jones, D. (2012). *Conversations with a person with Alzheimer's disease: A conversation analytic study*. Unpublished PhD dissertation, University of York, York, UK.

Kennard, C. (2009). Caregiver tips on managing confusion in Alzheimer's disease. Retreived from http://www.healthcentral.com/alzheimers/c/57548/78464/caregiver-tips

Lawson, J. S., & Barker, M. G. (1968). The assessment of nominal dysphasia in dementia: the use of reaction time measures. *British Journal of Medical Psychology*, *41*, 414–441.

Local, J., & Wootton, T. (1995). Interactional and phonetic aspects of immediate echolalia in autism: A case study. *Clinical Linguistics & Phonetics*, *9*, 155–184.

Martin, A., & Fedio, P. (1983). Word production and comprehension in Alzheimer's disease: The breakdown of semantic knowledge. *Brain and Language*, *19*, 124–141.

Marzanski, M. (2000). On telling the truth to patients with dementia. *Western Journal of Medicine*, *173*, 318–323.

Mates, A. W., Mikesell, L., & Smith, M. S. (2010). *Language, interaction, and frontotemporal dementia: reverse engineering the social mind*. London, UK: Equinox.

Mentis, M., Briggs-Whittaker, J., & Gramigna, G. D. (1995). Discourse topic management in senile dementia of the Alzheimer's type. *Journal of Speech and Hearing Research*, *38*, 1054–1066.

Mikesell, L. (2009). Conversational practices of a frontotemporal dementia patient and his interlocutors. *Research on Language & Social Interaction*, *42*, 135–162.

Mikesell, L. (2010). Repetitional responses in frontotemporal dementia discourse: Asserting agency or demonstrating confusion? *Discourse Studies*, *12*, 465–500.

Muller, N., & Guendouzi, J. A. (2002). Transcribing discourse: Interactions with Alzheimer's disease. *Clinical Linguistics & Phonetics*, *16*, 345–359.

Muller, N., & Guendouzi, J. A. (2005). Order and disorder in conversation: encounters with dementia of the Alzheimer's type. *Clinical Linguistics & Phonetics*, *19*, 393–404.

Muller, N., & Wilson, B. T. (2008). Collaborative role construction in a conversation with dementia: An application of systemic functional linguistics. *Clinical Linguistics & Phonetics*, *22*, 767–774.

Nebes, R. D. (1985). Preservation of semantic structure in dementia. In H. Ulatowska (Ed.), *The aging brain* (pp. 109–122). San Diego: College-Hill Press.

Orange, J. B., Lubinski, R. B., & Higginbotham, J. (1996). Conversational repair by individuals with dementia of the Alzheimer's type. *Journal of Speech and Hearing Research*, *39*, 881–895.

Perkins, L., Whitworth, A., & Lesser, R. (1998). Conversing in dementia: A conversation analytic approach. *Journal of Neurolinguistics*, *11*, 33–53.

Ramanathan, V. (1994). Interactional differences in Alzheimer discourse: An examination of AD speech across two audiences. *Language in Society*, *23*, 31–58.

Ripich, D., & Terrell, B. (1988). Patterns of discourse cohesion and coherence in Alzheimer's disease. *Journal of Speech and Hearing Disorders*, *53*, 8–15.

Ripich, D., Vertes, D., Whitehouse, P., Fulton, S., & Ekelman, B. (1991). Turn-taking and speech act patterns in the discourse of senile dementia of the Alzheimer's type patients. *Brain and Language*, *40*, 330–343.

Ritchie, K., & Touchon, J. (1992). Heterogeneity in senile dementia of the Alzheimer type: Individual differences, progressive deterioration or clinical sub-types? *Journal of Clinical Epidemiology*, *45*, 1391–1398.

Pomerantz, A. (1986). Extreme case formulations: A way of legitimizing claims. *Human Studies*, *9*, 219–230.

Sabat, S. (1991a). *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford, UK: Blackwell.

Sabat, S. (1991b). Turn-taking, turn-giving and Alzheimer's disease: A case study in conversation. *Georgetown Journal of Language and Linguistics*, *2*, 161–175.

Schellenberg, G. D. (1995). Genetic dissection of Alzheimer disease, a heterogeneous disorder. *Proceedings of the National Academy of Sciences of the United States of America*, *92*, 8552–8559.

Schermer, M. (2007). Nothing but the truth? On truth and deception in dementia care. *Bioethics*, *21*, 13–22.

Shuttleworth, E., & Huber, S. (1988). The naming disorder of dementia of Alzheimer type. *Brain and Language*, *34*, 222–234.

Sidnell, J. (2010). *Conversation analysis: An introduction*. Sussex, UK: Wiley-Blackwell.

Small, J. A., & Perry, J. (2005). Do you remember? How caregivers question their spouses who have Alzheimer's disease and the impact on communication. *Journal of Speech, Language, and Hearing Research*, *48*, 125–136.

Spilkin, M., & Bethlehem, D. (2003). A conversation analysis approach to facilitating communication with memory books. *Advances in Speech-Language Pathology*, *5*, 105–118.

Stivers, T., Mondada, L., & Steensig, J. (2011). *The morality of knowledge in conversation*. Cambridge, UK: Cambridge University Press.

Stribling, P., Rae, J., & Dickerson, P. (2009). Using conversation analysis to explore the recurrence of a topic in the talk of a boy with an autism spectrum disorder. *Clinical Linguistics & Phonetics*, *23*, 555–582.

Tuckett, A. G. (2011). The experience of lying in dementia care: A qualitative study. *Nursing Ethics*, *19*, 7–20.

Watson, C. M., Chenery, H. J., & Carter, M. S. (1999). An analysis of trouble and repair in the natural conversations of people with dementia of the Alzheimer's type. *Aphasiology*, *13*, 195–218.

Wechsler, D. (1981). *WAIS – R manual*. New York, NY: Psychological Corporation.

Wilensky, A. (2000). *Passing for normal*. London, UK: Simon & Schuster Ltd.

Wilkinson, R. (1999). Sequentiality as a problem and resource for intersubjectivity in aphasic conversation: analysis and implications for therapy. *Aphasiology*, *13*, 327–343.

Wilkinson, R., Beeke, S., & Maxim, J. (2010). Formulating actions and events with limited linguistic resources: Enactment and iconicity in agrammatic aphasic talk. *Research on Language and Social Interaction*, *43*, 57–84.

Williams, V. (2011). *Disability and discourse: Analyzing inclusive conversation with people with intellectual disabilities*. Sussex, UK: Wiley-Blackwell.

Wilson, B. T., Muller, N., & Damico, J. S. (2007). The use of conversational laughter by an individual with dementia. *Clinical Linguistics & Phonetics*, *21*, 1001–1006.

Wood-Mitchell, A., Waterworth, A., Stephenson, M., & James, I. (2006). Lying to people with dementia: sparking the debate. *Journal of Dementia Care*, *14*, 30–31.

Wootton, A. J. (1997). *Interaction and the development of mind.* Cambridge, UK: Cambridge University Press.

## Author Biography

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# Appendix 1

*Transcription convention*

| | |
|---|---|
| [overlap] | Brackets: Onset and offset of overlapping talk. |
| ° | Equals sign: Utterances are latched or ran together, with no gap of silence. |
| - | Hyphen: Preceding sound is cut off/self-interrupted. |
| ↑word↓ | Up/Down arrows: indicate pitch fluctuations up or down. |
| (0.0) | Time pause: Silence measured in seconds and tenths of seconds. |
| (.) | Parentheses with a period: A micropause of less than 0:2 s: |
| : | Colon(s): Preceding sound is extended or stretched; the more the longer. |
| . | Period: Falling or terminal intonation. |
| | ,Comma: Continuing or slightly rising intonation. |
| ? | Question mark: Rising intonation. |
| underline | Underlining: Increased volume relative to surrounding talk. |
| soft | Degree signs: Talk with decreased volume relative to surrounding talk. |
| >fast< | Greater-than/less-than signs: Talk with increased pace relative to surrounding talk. |
| <slow> | Less-than/greater-than signs: Talk with decreased pace relative to surrounding talk. |
| .h | Superscripted periods preceding h's: Inbreaths; the more the longer. |
| h | H's: Outbreaths (sometimes indicating laughter); the more the longer. |
| hah/heh | Laugh token: Relative open or closed position of laughter. |
| (that)/(hat) | Filled single parentheses: Transcriptionist doubt about talk. Alternative hearings. |
| ((Cough)) | Filled double parentheses: Additional details, or an event/sound not easily transcribed. |