Diagnostic communication in the memory clinic: a conversation analytic perspective

This item was submitted to Loughborough University's Institutional Repository by the author.

Citation: PEEL, E., 2015. Diagnostic communication in the memory clinic: a conversation analytic perspective. Aging & Mental Health, 19(12), pp. 1123-1130.

Additional Information:

• This is an Open Access Article. It is published by Taylor and Francis under the Creative Commons Attribution 4.0 Unported Licence (CC BY). Full details of this licence are available at: http://creativecommons.org/licenses/by/4.0/

Metadata Record: https://dspace.lboro.ac.uk/2134/21011

Version: Published

Publisher: © The Author. Published by Taylor and Francis

Rights: This work is made available according to the conditions of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International (CC BY-NC-ND 4.0) licence. Full details of this licence are available at: https://creativecommons.org/licenses/by-nc-nd/4.0/

Please cite the published version.
Diagnostic communication in the memory clinic: a conversation analytic perspective

Elizabeth Peel

To cite this article: Elizabeth Peel (2015) Diagnostic communication in the memory clinic: a conversation analytic perspective, Aging & Mental Health, 19:12, 1123-1130, DOI: 10.1080/13607863.2014.1003289

To link to this article: http://dx.doi.org/10.1080/13607863.2014.1003289

© 2015 The Author(s). Published by Taylor & Francis.

Published online: 03 Feb 2015.

Article views: 1091

View related articles

View Crossmark data

Citing articles: 1 View citing articles
Diagnostic communication in the memory clinic: a conversation analytic perspective

Elizabeth Peel*

Institute of Health & Society, Psychology Department, University of Worcester, Worcester, UK

(Received 23 September 2014; accepted 27 December 2014)

Objectives: Whether and how patients should be told their dementia diagnosis, has been an area of much debate. While there is now recognition that early diagnosis is important for dementia care little research has looked at how dementia-related diagnostic information is actually verbally communicated. The limited previous research suggests that the absence of explicit terminology (e.g., use of the term Alzheimer’s) is problematic. This paper interrogates this assumption through a conversation analysis of British naturalistic memory clinic interaction.

Method: This paper is based on video-recordings of communication within a UK memory clinic. Appointments with 29 patients and accompanying persons were recorded, and the corpus was repeatedly listened to, in conjunction with the transcripts in order to identify the segments of talk where there was an action hearable as diagnostic delivery, that is where the clinician is evaluating the patient’s condition.

Results: Using a conversation analytic approach this analysis suggests that diagnostic communication, which is sensitive and responsive to the patient and their carers, is not predicated on the presence or absence of particular lexical choices. There is inherent complexity regarding dementia diagnosis, especially in the ‘early stages’, which is produced through and reflected in diagnostic talk in clinical encounters.

Conclusion: In the context of continuity of dementia care, diagnostic information is communicated in a way that conforms to intersubjective norms of minimizing catastrophic reactions in medical communication, and is sensitive to problems associated with ‘insight’ in terms of delivery and receipt or non-receipt of diagnosis.

Keywords: Alzheimer’s disease; conversation analysis; dementia; diagnosis; health communication; qualitative methods

Introduction

Dementias are a complex set of conditions estimated to affect 25 million people worldwide (Ferri et al., 2005), and 850,000 people in the UK alone (Prince et al., 2014). Following the publication of the National Dementia Strategy (Department of Health [DoH], 2009) and the Prime Minister’s challenge on dementia (2012), it has been widely reported that less than half of those living with dementia in England have a formal diagnosis. Government policy emphasizes the importance of early diagnosis to allow for timely intervention and access to services and support (Department of Health [DoH], 2012). Thus the topic of dementia diagnosis currently has a high profile, but diagnosis within the dementia field is not uncontested, particularly in the case of ‘early’ diagnosis (Hansen, Hughes, Routley, & Robinson, 2008). There have been concerns voiced in the literature about diagnosing dementia (Bunn et al., 2012; Iliffe, Manthorpe, & Eden, 2003; Koch & Iliffe, 2010; Moore & Cahill, 2013). These concerns have focused on the potentially negative impacts of diagnosis on the patient (e.g., the negative effects of stigma, labelling and creating anxiety), and carer (longer time in a stressful role). Diagnosis has also been identified as potentially problematic for the provision of dementia services, in terms of specialist services being overloaded, and the inherent complexity in diagnosing dementia (e.g., Bunn et al., 2012; Iliffe, Manthorpe, & Eden, 2003; Koch & Iliffe, 2010; Moore & Cahill, 2013).

In contrast, there are thought to be a wide range of benefits to the patient, the family and caregivers, and to resources and services, in diagnosing dementia earlier, and it has been suggested that these far outweigh the concerns (Moore & Cahill, 2013). Timely diagnosis – which is increasingly the preferred term (Brooker, La Fontaine, Evans, Bray, & Saad, 2014) – enables the early initiation of treatment, including pharmacological and psychosocial interventions such as cognitive stimulation therapy, and it has been demonstrated that this can delay admission to nursing homes and time to dependency (Leung et al., 2011). It has also been suggested that ‘catastrophic’ reactions to the diagnosis of dementia from individuals are relatively uncommon (Lecouturier et al., 2008; Moore & Cahill, 2013).

The existing literature suggests that health professionals (particularly general practitioners but also specialist psychiatrists and neurologists) find the diagnostic delivery process more challenging than patients and carers (Kaduszkiewicz, Bachmann, & van den Bussche, 2008; Hellström & Torres, 2013). From the late 1990s onwards there has also been a gradual move away from a focus on the rather paternalistic question about whether the person with dementia should be told ‘the truth’ (e.g., Fearnley,
Mclennan, & Weak, 1997) or not, as well as an increased acknowledgement that diagnosis is a process rather than a one-off event (e.g., Hellström & Torres, 2013). Limited previous research has focused on the disclosure or delivery of the dementia diagnosis in practice, either utilizing interview data from health care professionals (e.g., Kissel & Carpenter, 2007; Moore & Cahill, 2013) and/or recipients (e.g., Aminzadeh, Byzsowski, Molnar, & Eisner, 2007; Karnieli-Miller, Werner, Aharon-Peretz, Sinoff, & Eidelman, 2012a) rather than a one-off event (e.g., Hellström & Torres, 2013) or not, as well as an observation of clinical encounters, a Canadian study noted that patients displayed a more immediately negative reaction to an Alzheimer’s disease diagnosis compared to vascular dementia (Aminzadeh et al., 2007; Karnieli-Miller, Werner, Aharon-Peretz, & Eidelman, 2007; Karnieli-Miller, Werner, Aharon-Peretz, Sinoff, & Eidelman, 2012b). This research has highlighted a number of issues regarding dementia diagnosis delivery, including an avoidance of the terms ‘dementia’ or ‘Alzheimer’s disease’ (e.g., Karnieli-Miller et al., 2007). This is typically positioned as problematic. Moore and Cahill (2013, p. 78) refer to the observed lack of usage of explicit dementia-related terminology as talking covertly about the illness using euphemisms such as “memory problems” or “confusion”. They go on to reflect that of the general practitioners they interviewed: ‘Curiously none appeared to be aware that they themselves might also be contributing to this stigma by virtue of (in most cases) their either avoiding getting involved in dementia diagnosis or alternatively using euphemisms when discussing the illness with their patients’ (p. 82). Kissel and Carpenter (2007) have highlighted that US physicians open ‘the disclosure conversation’ ‘by emphasizing a positive finding before delving into the diagnosis’:

One physician reported that she starts with something like this: ‘There were no abnormalities on the examination. Physically you’re quite healthy. One of the things we wanted to discuss today was memory and thinking . . .’. Physicians described this tactic as ‘easing [the patients] into the more difficult part’ of the conversation. A similar strategy is to put a ‘positive spin’ on the otherwise negative diagnosis. . . . one physician’s approach is to say, ‘that it’s a very slowly changing illness, and that finding out early is healthy and good because there is a lot that can be done and that there is room for optimism about what the future holds.

(p. 277)

In terms of the small number of studies based on direct observation of clinical encounters, a Canadian study noted that patients displayed a more immediately negative reaction to an Alzheimer’s disease diagnosis compared to vascular dementia (Aminzadeh et al., 2007) but this observation was based on field-notes of the encounters rather than being demonstrated through the analysis. Israeli research, using a grounded theory approach (Karnieli-Miller et al., 2007, 2012b) has suggested that the notion of a ‘triadic encounter’ – between the patient, their companion and the physician in the memory clinic – is a misnomer. In their recordings of 25 diagnostic disclosures in memory clinic visits, ‘the discourse moved from direct conversation with the patient to talking about or ignoring him/her regarding treatment decisions’ (2012b, p. 389). The interactional structure they identify in these encounters is positioned as problematic: ‘avoiding exclusion is a difficult but an essential element toward practising “patient-centred care” and preserving the patient’s dignity’ (p. 389). In a phenomenological study of clinic encounters Karnieli-Miller et al. (2007) observed that interactions are kept short, elaboration is avoided, understanding is not checked, explicit terminology (described as the A word and the D word, p. 312) is avoided and that the use of fractured sentences evidences ‘reluctance to make a candid disclosure of the diagnosis’ (p. 313). They suggest that these discursive practices during diagnostic delivery ‘may be perceived as different ways of dulling the impact’ (p. 307) of dementia diagnosis and ‘may violate basic moral and legal rights and may also deprive patients and caregivers of some of the benefits of early disclosure of diagnosis’ (p. 313). Taken together, these studies focusing on the process of diagnostic delivery – in terms of breaking bad news in this context, prognosis and treatment – highlight some of the difficulty of this task, but they are also value laden and carry a heavy freight in terms of how these interactions should proceed or could be produced differently.

There is a substantial literature on the delivery of bad news in medical encounters drawing on number of traditions including conversation analysis (e.g., Heritage & Maynard, 2006; Maynard & Heritage, 2005). Some experimental research also suggests that the use of indirect language is used by experienced doctors in order to manage the ‘situational dilemma’ of delivering bad news (del Vento, 2007). This paper adds to the current literature on dementia diagnosis by applying conversation analytic insight to a small corpus of naturally occurring UK memory clinic interactions, within a service delivery model wherein a secondary care service is embedded in primary care and continuity of care and support is emphasized. One of the strengths of this form of analysis – which foregrounds the sequential organization of talk – is that the co-construction of meaning is made visible through the analysis and subject to analytic scrutiny (Heritage & Maynard, 2006).

Focusing on medical communication is not only important in a generic sense (Bensing, Verhaak, van Dulmen, & Visser et al., 2000); conversation analysis particularly, it has been suggested, ‘fits with biopsychosocial, patient-centred and relationship-centred approaches’ (Maynard & Heritage, 2005, p. 428). By examining the fine-grained nature of these co-constructions in some depth, arguably, the communicative spaces for the active engagement of people living with dementia and their families can be understood and widened (Antaki, 2011). Thus the aim is to interrogate the existing literature that has labelled the communication of dementia diagnosis as ‘fraught with the problems, perils and pitfalls that hinder optimal, efficacious, ethical and compassionate management of demented patients [sic]’ (Karnieli-Miller et al., 2007, p. 313) and, ultimately, contribute to patient-oriented advice on the
diagnostic process which is grounded more firmly in the actual business to which it relates.

Methodology
Following Social Care Research Ethics Committee and National Health Service Research and Development approval, 18 memory clinic appointments were recorded over four memory clinics between March and July 2012 with 15 patients (mean age 76.66 years, range 55–92 years) and 14 accompanying persons (13 relatives and one neighbour). This resulted in nine and a half hours of video-recording in the setting. A further four appointments were observed during the data-collection period plus an entire memory clinic (3 hours 15 minutes) prior to the data-collection phase, therefore around 15 hours were spent in the setting. These data form part of a larger project focused on dementia care and communication more broadly (see also Harding & Peel, 2013; Peel, 2014; Peel & Harding, 2014). The video-data corpus was repeatedly listened to, in conjunction with the transcripts in order to identify the segments of talk where the clinician was engaged in delivering an action hearable as diagnostic delivery – that is, according to Heritage and Maynard (2006), where the doctor is evaluating the patient’s condition. This resulted in six interactions with five different patients, which amounted to about 14 minutes of talk in total. In the analysis that follows names and any other identifying information have been changed.

Analysis and discussion
The first extract between Emily (the patient) her daughter Beatrix and the clinician comes toward the end of the 43 minute appointment following history taking and a cognitive assessment. The doctor has drawn the appointment to a close by saying that he will put all that in a letter which ‘she can share with the family’ if she wants and Emily say ‘yes, thank you’. Earlier in the interaction the doctor says ‘What I would say is that - I mean you have significant changes in your memory. It’s not huge but it’s there. It’s marvellous that you’re doing all the things you’re doing, because doing things is good for your brain’. This is reminiscent of what Kissel and Carpenter (2007) describe as the ‘positive spin’ physicians report using when delivering dementia diagnoses. Emily has probable Alzheimer’s and is followed up at the next memory clinic the following month with a home visit. Extract 1 starts at the point where Beatrix, the daughter, starts to ask a question (so was the-) which she then self-repairs to a declarative question about the outcome of her mother’s brain scan. The doctor could have started his turn at ‘okay’ but when he doesn’t speak at this point she downgrades her epistemic authority (Heritage & Raymond, 2005) in deference to the doctor (‘I think’). Beatrix – through her reformulated question – is seeking clarification on the outcome from the scan in a way that positions a problem as a dispreferred next turn (‘all okay’), but also places the clinician in position of high epistemic authority.

Extract 1: MC1 Emily and Beatrix

<table>
<thead>
<tr>
<th>line</th>
<th>text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bea: So was the scan that was all okey?</td>
</tr>
<tr>
<td>2</td>
<td>()</td>
</tr>
<tr>
<td>3</td>
<td>Bea: &gt;I think&lt; wasn’t it.</td>
</tr>
<tr>
<td>4</td>
<td>Dr.: The- the- the scan shows w-well it. hh so: me- er some changes that-</td>
</tr>
<tr>
<td>5</td>
<td>that- that occur as we get older=</td>
</tr>
<tr>
<td>6</td>
<td>Bea: “Mhm”</td>
</tr>
<tr>
<td>7</td>
<td>Dr.: &gt;that is there are&lt; there’s no tu: mours, there’s no vascular, no BI: g vessel changes=</td>
</tr>
<tr>
<td>8</td>
<td>Bea: Mhm.</td>
</tr>
<tr>
<td>9</td>
<td>Dr.: &gt;that are demonstrated&lt; but- but there- there is a degree of redu: ced er volume</td>
</tr>
<tr>
<td>10</td>
<td>but some things er</td>
</tr>
<tr>
<td>11</td>
<td>Bea: Mhm.</td>
</tr>
<tr>
<td>12</td>
<td>Dr.: of er brain substance .hh and that’s significant ander as we’ve seen</td>
</tr>
<tr>
<td>13</td>
<td>during the afternoon .h mum can do quite a lot of things quite well</td>
</tr>
<tr>
<td>14</td>
<td>but some things er</td>
</tr>
<tr>
<td>15</td>
<td>Bea: Mhm.</td>
</tr>
<tr>
<td>16</td>
<td>Dr.: sh- it ery’ know the words don’t quite co:me and the- the calculations</td>
</tr>
<tr>
<td>17</td>
<td>were corre:ct[act] ually=</td>
</tr>
<tr>
<td>18</td>
<td>Bea: [”Mhm”]</td>
</tr>
<tr>
<td>19</td>
<td>Dr.: &gt;and things aren’t quite&lt; an- er sh- she cou-couldn’ t hold on t- to</td>
</tr>
<tr>
<td>20</td>
<td>words so there are significant and- and important changes the: re .hh</td>
</tr>
<tr>
<td>21</td>
<td>how that pans out in the longer run=</td>
</tr>
<tr>
<td>22</td>
<td>Bea: [ Mhm. ] [ Mhm. ]</td>
</tr>
<tr>
<td>23</td>
<td>Dr.: &gt;we’ ll just have to&lt; see.</td>
</tr>
<tr>
<td>24</td>
<td>Bea: Yep.</td>
</tr>
<tr>
<td>25</td>
<td>Dr.: Okay.</td>
</tr>
<tr>
<td>26</td>
<td>Bea: Mhm.</td>
</tr>
<tr>
<td>27</td>
<td>Dr.: Oh well t’ hh thank you very much for your ti::me.</td>
</tr>
<tr>
<td>28</td>
<td>Bea: It’s a pleasure. Thank you for comin an putting up with us</td>
</tr>
</tbody>
</table>

In line 4, the doctor starts responding then uses ‘well’ which projects that the answer is not going to be straightforward (Schegloff & Lerner, 2009) before taking a breath and normalizing the results (‘some changes that occur as we get older’). In line with the conversation analytic literature on delivery of bad news in medical encounters (e.g., Heritage & Maynard, 2006) there is little ‘atypical’ about the equivocal language used in Extract 1. What we see in this interaction are dysfluencies such as self-repair and talk in lines 7–10 that hedges what the scan has not ‘demonstrated’ before a similarly dysfluent delivery of what the scan has shown ‘there- there is a degree of redu: ced er volume of er brain substance .hh and that’s signifi- cant’ (lines 10–13). In keeping with the receipt of diagnostic information in other medical contexts (e.g., Heath, 1992) this information is not received as news, but rather is minimally received by the daughter and met with silence from the patient. The doctor then moves on without pause to the more proximate evidence from the
cognitive assessment that has taken place earlier in the appointment implicating both daughter and patient (‘as we’ve seen during the afternoon’) in his assessment of the situation. Although the patient is referred to in the third person (‘mum’ line 14, ‘she’ line 20), the doctor’s gaze shifts to the patient when presenting the good aspects of the bad news – on ‘quite well’ (line 14). The word ‘quite’ is also used as a softener on four occasions. We can see in response to the daughter’s query about the scan results an interactional pattern where positives (e.g., ‘no tumours’; ‘the calculations were correct actually’) come before rather non-specific negatives (e.g., ‘a degree of reduced brain volume’, ‘couldn’t hold on to words’). And in a rather ‘veiled’ way (Bergmann, 1992), the seriousness of the diagnosis is communicated through the words ‘significant’ and ‘changes’.

As well as a high degree of sensitivity being displayed in this extract we see, contrary to Karnieli-Miller et al.’s (2012b) observation that by the end of the diagnostic encounter the patient herself is being ignored, something more complex occurring. The doctor’s shift in focus to the patient’s daughter, rather than the patient herself, has been prompted by the daughter, in line 1, and the patient herself draws the exchange to a close (line 28). Emily holds her head before moving her hand away as she says ‘Oh well’, suggesting both a tacit acknowledgement of the information and (perhaps) an acceptance of its inevitability. But ‘thank you very much for your time’ arguably steps away from a more explicit articulation of receipt of this information (a thanking for information or expertise) through this more formulaic closing. Overall, this example would suggest that while explicit diagnostic information is not delivered (i.e., probable Alzheimer’s disease) the receipt of the information is in step with diagnostic delivery as it occurs in other medical settings (i.e., minimal) and conforms to the intersubjective norms of minimizing catastrophic reactions in medical communication (Maynard & Frankel, 2006).

We will now move on to consider Extract 2. Jackie, the patient, is accompanied by her two daughters Tess and Mandy. In terms of the broader landscape of the interaction, the evaluation of Jackie’s condition again comes towards the end of the appointment after undergoing a cognitive assessment. By contrast, the talk here is not prompted by a person accompanying the patient pursuing further understanding of the diagnostic outcome of the medical investigations, but rather an assessment of the situation initiated by the doctor, which can loosely be glossed as summing up and closing the consultation. Another broader feature of this extract to note is that the doctor, contra Karnieli-Miller et al.’s (2012b) observation that clinicians move away from talking to the patient, unambiguously addresses the patient herself both verbally (‘you’ve’) and through gaze and gestures. We can see, in line 4, a sensitivity displayed in conveying where the source of the concern lies; immediately after ‘your daughters’ are mentioned there is the vague and mitigated phrase ‘and I think people are just a bit worried ’. Interestingly, in line 7, the doctor rather than continuing to report on the external findings from the cognitive assessment, self-repairs at (‘but it’) and seeks affiliation from Jackie, the patient, in a more personally implicating way (‘you can see’).

Extract 2: MC3 Jackie, Tess and Mandy

1 Dr.: Well you’ve done very well we’ve been working you very hard, haven’t we
2 we .hh so it’s lovely to see ya[ tch] we
3 Jac: [ Mmm.]
4 Dr.: an and- and- and meet your daughters er and I think people are just a
5 bit worried that perhaps you need a little bit of extra help and that
6 er with your memory (0.2) it’s still pretty good for lots of things but it- you can see there are some things >you can’t quite do< .hh
7 [ what’s al-]
8 9 Jac:[ When you ] get to eighty-four yo:u (.)
9 Dr.: (2.0) I was gonna say what’s all that about? and you’ve=
10 Man: “uhah”
11 Dr.: —provided er probably the an:swer
12 Tes: [ Mmm. ]
13 Jac: [ ‘Yes’]
14 Dr.: haven’t t[ you? ] probably the answer er the fact that you had that
15 bleee all those years ago might be relevant but it’s- but you made a
16 good recovery from it=
17 Tes:[ Mmmmm. ]
18 Jac: [ ‘Y’ av’].
19 Dr.: =and you’ve carried on life since haven’t you:
20 Tes: [ Mshmm. ]
21 Dr.: =and you’ve carried on life since haven’t you:
22 Dr.: =in your age
23 so on that- that- er but it’s age
24 like that t’ .hh er hm (. ) question is can we do anything to make that
25 a bit better?
26 Jac: I don’t think so?
27 Dr.: And er well you may be right you- you may be right t’ .hh it’s=
28 important that yo- that we keep you as fit as possible=
29 Tes: [ Mhm.]
30 Dr.: =in your general health isn’t it .hh and that-=>I mean one of< the
31 simple things is foo::d ((continues))

There have been a number of opportunities within the doctor’s turn for Jackie to align with him or to take a turn which is more than minimal – she nods at the ‘haven’t we’ on line 1–2 and ‘tuts’ after ‘lovely to see you’ on line 3. At ‘you can’t quite do’ (line 7) Jackie looks down, shakes her head rubbing her top lip and sniffs. When Jackie does start to speak in overlap with the doctor on
line 9 she offers a normalizing description of her circumstances, which offers ‘forget[ing]’ as a function of her chronological age. The doctor then partially aligns with Jackie in lines 12 and 15 saying that she’s provided ‘probably the answer’ before referring to a historical stroke she had experienced. In lines 22–25, the doctor — with lots of perturbations — ultimately concludes that this cognitive decline is ‘age-related’. That he self-repairs at ‘that-that-er but’ intimates great delicacy in the direction of travel towards a suggestion that possible ‘changes in the brain substance’ could be suggestive of vascular dementia. He then moves swiftly on in lines 24–25 to posing the question ‘can we do anything to make that a bit better?’. Jackie’s response (‘I don’t think so’) could indicate a lack of understanding of the potential significance of ‘changes in the brain substance’ but it could also signal stoicism and a recognition of decline. But that decline is produced as a product of normative cognitive ageing rather than as a potential sign of dementia. We can see, therefore, quite clearly the situational dilemma for the doctor in ‘pushing’ a firmer and more explicit diagnosis with Jackie. Jackie is a heavy smoker, who is currently not eating well or regularly and, therefore, a focus on ‘general health’ fits with a holistic patient-centred perspective that — as we have seen in the unfolding of this particular interaction — is sensitive to the patient’s expressed lack of ‘insight’ that her forgetfulness may be symptomatic of dementia. Ultimately, in this encounter there is uncertainty communicated in the contrast between ‘may’ (line 22) and ‘but’ (line 23) where a neurodegenerative diagnosis is stepped away from towards an ‘age-related’ diagnosis. Although Jackie was followed-up at a future appointment that interaction occurred outside the scope of this project, and therefore whether Jackie did get a ‘definitive’ diagnosis of vascular dementia or not is unknown.

Extract 3 is rather different to the previous two consultations (both first visits to the memory clinic) in that the diagnosis is reiterated to the patient, Bob, in a solo consultation following an uncomfortable interaction at the previous memory clinic wherein Bob’s wife, Annabel, complaining about the lack of support and service, which is subsequently defended by the doctor. He opens his response in overlap with Annabel with ‘[W- well I] mean .hh er I’m sitting here feeling a bit uncom-... then everythin’ and then quite portable let me... with a brain scan. Well... through all of that... crazy... that’s why he’s receiving the Aricept’. I present these data not to align with any particular interlocutor or to offer a commentary on the business of doing complaining within this particular healthcare setting, rather to make two initial observations. The first, is that the a-word and the d-word, as Karnieli-Miller et al. (2007) put Alzheimer’s disease and dementia do appear in the memory clinic data in this study, albeit rarely, and only when first used by the patient’s carer. Second, that the presence or absence of these terms is perhaps, at least in some contexts, less crucial to the ongoing business of interaction in the memory clinic than the existing literature on timely diagnosis might suggest. We join the interaction in Extract 3 after the doctor is re-pursuing an answer to the question ‘how’s your wife is she ok:y at the moment’.

Extract 3: MC4 Bob

1 Dr.: .hh cos sometimes sh- y’ know last time we saw the two of you>I mean<
2 she was quite troubled wasn’t t she quite stre:ssed.
3 Bob: Erm hhh(3.0)well it would’ve been nice if- erm if I had erm what was the thing that you were doing
4 Dr.: Alzheimer’s?
5 Bob: Alzheimer’s.
6 Dr.: Mm.
7 Bob: Erm would you s- y’ know you’re re- you’re re- you’re c-covering all ba:ses well ermer- would be a- is it useful that if I had a- (.) y’ know hh
8 Dr.: A brain scan. Well-
9 Bob: I have had one actually
10 Dr.: you’ve had a brain scan
11 Dem: Yeah.
12 Dr.: an- and we are treating you on
13 Bob: And I went round through the
14 Dr.: through all of that
15 Bob: No-no- what is it erm (. I’ve only had one and it didn’t show anything er
16 Dr.: Well it showed some: changes and on that basis and your
17 [clinical condition
18 Bob: [W-
19 Dr: we do say that you have the early stages of Alzheimer cha:nges that’s why you’re on the treatment that you’re on.
20 Dr.: That’s why you’re now on the patches .hh and that’s why we (. ) tried
21 with the Aricept previously .hh
22 Bob: Yeah.
23 Dr.: but it’s complicated isn’ t it cos as you’ve said for many many years
24 Bob: Mm oh f-
25 Dr.: thankfully for the moment

(continued)
At the end of this excerpt the doctor then moves on to say that as things have been pretty difficult lately he would like to see them once a month, which is important to highlight as this interaction is within the context of ongoing continuity of care within the memory clinic, as are the other cases discussed. The sequence of talk to line 17 is a rather frank discussion of the diagnosis, mentioning explicitly the word ‘Alzheimer’s’, which Bob repeats. Bob appears to be pursuing a description of the experience of being in the bore of the MRI scanner, in line 15, he moves his arms forward which is suggestive of being within the scanner. The doctor then offers an evaluative interpretation of that experience (‘though all of that’) which Bob rejects, and then in lines 17–18, he categorically states that ‘it didn’t show anything’.

What this first section of these data clearly highlights is that there is — at least for this patient at this time — no necessary correspondence between the explicit use of the term Alzheimer’s and a recognition and understanding that dementia is what the person is experiencing. In line 8,

after the doctor’s naming of Alzheimer’s, Bob’s use of the idiomatic phrase ‘covering all bases’ indicates a much less definitive understanding of the diagnosis; one that is exploratory and dealing with every possibility. In lines 24 and 27, Bob offers a minimal receipt of ‘yeah’ in response to the clear diagnostic statement of ‘early stages of Alzheimer changes that’s why you’re on the treatment you’re on’. Then, in line 28, the doctor implicitly contrasts the ‘simplicity’ of the Alzheimer’s diagnosis with the complicatedness of the patient’s longstanding bipolar disorder. And this is also delivered as the opposite of ‘news’ through the phrase ‘as you’ve said’.

The very positive evaluation of the stability of Bob’s bipolar disorder ‘terrific’, line 38, then leads into an unambiguous statement (‘there’s no doubt’) about the decline in Bob’s communicative ability, memory functioning and decision-making capacity. In line 41, the doctor reintroduces mention of Bob’s wife — ‘as described by your wife last time’ — which then prompts an account from Bob about his wife’s lack of understanding of ‘when I’m on song or backwards’ to which he gets a series of experientially affirming responses from the doctor (in lines 46, 49, 51, 53, 55). The responses ‘quite’ and ‘that’s true’ and ‘it does’ are not simply affiliative but display an orientation to these turns being indicative of the nature of Alzheimer’s — and, therefore, communicating an expert assessment of Bob’s stance on his difficulties. As well as being a closing turn in line 59, the doctor explicitly does not take this opportunity to re-state the progression of the Alzheimer’s disease decline, but rather offers a supportive assessment of Bob’s stance that his memory ‘is coming back’ which also conveys how Bob ‘feels’ may not reflect the reality.

Conclusion

Clinical decision-making within the memory clinic context is a complex business, not least because of the number of different diagnoses which are applicable under the neurodegenerative disorder umbrella, the variability in underlying pathologies, and the points during the process at which diagnostic (and prognostic) information is sought by carers or patients. From a conversation analytic perspective diagnosis is the doctor’s evaluation of the patient’s condition (Heritage & Maynard, 2006). The interactions that have been presented in this paper, and in the context of dementia, or possible dementia, diagnosis specifically highlights not only a considerable complexity needed within this context but also knotty interpersonal dynamics, which are being managed on an unfolding basis. This analysis resonates with conversation analytic findings that highlight that a bad news diagnosis is shrouded in various ways (e.g., Maynard & Frankel, 2006). The conversation analytic literature has also highlighted that diagnoses, within the primary care encounter at least, tend to be delivered in a way that do not wholly rely ‘on authority’, and there tends not to be much by way of acknowledgement or agreement from patients (Heath, 1992; Heritage & Maynard, 2006; Peräkylä, 1998, 2002, 2006). As Heritage and Maynard
patients (Karnieli-Miller et al., 2007, p. 307), we saw in these data through their discursive practices ‘dulling the impact’ are, in memory clinic interaction, ‘normalizing’ or health care professionals, patients and carers. 

who were themselves normalizing their experience instances where the doctor was interacting with patients information. The communicative business of dementia interactions as well as acceptance, or not, of diagnostic (or lack of insight) impacts the unfolding shape of these also indicated that complexity associated with ‘insight’ understanding by the patient (Extract 3). The analysis has

naming of Alzheimer’s does not necessarily facilitate itly articulated for diagnostic information to be communi-

(2006, p. 16) summarize ‘this manifests itself in little or no patient responsiveness to clinicians’ diagnostic statements’.

What was not evident, however, in these data is what Maynard (1992) identified as the ‘perspective-display sequence’, wherein space is created for the recipient to produce the bad news, which the health professional then confirms. It would be interesting to have larger corpora of ‘diagnostic delivery’ exchanges in dementia care settings in order to explore whether this difference in recipient-design relates to how dementia is ‘different’ (St Clair Tullo et al., 2014) — especially with regard to capacity, understanding and patient insight into the condition. What this analysis suggests is that there may be an inherent complexity regarding dementia diagnoses — particularly in the ‘early stages’ — which is both produced through and reflected in the diagnostic language used in this context. Larger data-corpora of talk within the memory clinic context are also needed to disaggregate to what extent the interactional texture exhibited in this setting is associated with clinical uncertainties linked with cognitive changes or dementia per se (as in the example of Jackie’s condition being vascular change associated with normal cognitive ageing or transient ischaemic attack’s rather than vascular dementia) or to interactional features associated with ‘shrouding’ bad news more generally. Supplementary data derived from interviews with patients, accompanying persons and health professionals would also further assist in understanding dementia diagnosis in the UKs shifting policy and health care climate.

As indicated by Kissel and Carpenter’s (2007) study with 10 US doctors, it is not that precise terminology are ‘unusable’ or deliberately withheld — indeed the physicians they interviewed reported intending to use unequivocal and precise diagnostic labels — it is that ‘many physicians admitted to being flexible with their diagnostic language’ (p. 277). A key contribution of this analysis is that it troubles the notion conveyed by the existing literature (e.g., Karnieli-Miller et al., 2007) that medical professionals’ not using the a-word or the d-word is intensely problematic. The small number of cases that have been discussed within this paper suggests that some interactions do not necessarily need the diagnostic labels to be explicitly articulated for diagnostic information to be communicated (Extracts 1 and 2). Moreover, the unambiguous naming of Alzheimer’s does not necessarily facilitate understanding by the patient (Extract 3). The analysis has also indicated that complexity associated with ‘insight’ (or lack of insight) impacts the unfolding shape of these interactions as well as acceptance, or not, of diagnostic information. The communicative business of dementia diagnosis — in some health care contexts and for some patients — is an ongoing, repetitive discussion between health care professionals, patients and carers.

Rather than suggesting that health care professionals are, in memory clinic interaction, ‘normalizing’ or through their discursive practices ‘dulling the impact’ (Karnieli-Miller et al., 2007, p. 307), we saw in these data instances where the doctor was interacting with patients who were themselves normalizing their experience (Jackie, Bob) or talking in ways that were suggestive of dulling the impact of the diagnostic information provided in the memory clinic — in Jackie’s case possible vascular dementia. What this analysis of actual consultations in the memory clinic illustrates is that there are situational dilemmas for the smooth running of interactions in this context that are mediated by a complex interplay of concerns. At a broader level, some of these concerns likely relate to political and fiscal emphasis on increasing diagnosis rates (Campbell, 2014) and the use of deception in clinical practice remaining a live issue in dementia care (St Clair Tullo et al., 2014). Instead of making value-laden statements about what constitutes ‘normalizing’ (or indeed ‘catastrophizing’) talk in this dementia care context, there is great potential to learn about ‘effective’ diagnostic delivery, by further exploring dementia care conversations in the memory clinic and beyond.

Acknowledgements

With very grateful thanks to everyone who participated in the Dementia Talking: Care, Conversation and Communication project, and to Merran Toerien, Danielle Jones and other members of the Dementia Communications Research Network who were at the Centre for Dementia Research (CEDER) Conference at Linköping University (October, 2014) for helpful comments on an earlier version. All opinions expressed in this article are those of the author and not necessarily those of the funding body.

Disclosure statement

No potential conflict of interest was reported by the author.

Funding

This research was supported by a British Academy Mid-Career Fellowship [MC110142].

References


Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., … Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and


