You are happy and safe: discourse analysis of diagnostic disclosure of dementia

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Aims

“to explore the way the meaning of dementia was co-constructed by people being given a diagnosis, accompanying relatives and practitioners in the appointment in which the person was given their diagnosis”

• how is dementia spoken about in a diagnostic disclosure session?

• what is the nature of the interaction between the professional, the person with dementia and the family member?
Method

• Discourse analysis – the way meaning is *constructed* (rather than *conveyed*)
• 10 recordings

People with dementia
• >60 years – 6 women, 2 men
• 5 diagnosed with Alzheimer’s disease, 1 vascular dem, 2 mixed

Professionals
Psychiatrist (6), clinical psychologist (3), OT (1).
Georgaca & Avdi 5-point framework (2012)

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<td>Discourses, ideological dilemmas, interpretative repertoires</td>
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<td>Subjectivity, interpellation, location</td>
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1. Language as construction

Dementia as memory problem/condition

Prof 5: What you have is a memory problem which is caused by circulation to the brain.

Prof 8: Now in vascular conditions there is no tablet we can give to control the memory you know.

Client 3: What’s the difference between memory loss and Alzheimer’s. Is it always Alzheimer’s?

Prof 3: It’s not always Alzheimer’s. There are, there are different types of dementia.
P5: Now, the second support, which is [in] this leaflet, is a Dementia Adviser. That’s her name and number.

F5: Yes.

P5: It’s worth giving her a call. I really I would recommend that. They will come and have a chat with you and link you into all the various supports that are there.

F5: Right. Okay.

P5: And that’s really good.

F5: Are those supports that are free or to be paid for?

P5: Free, free, it’s entirely free.

F5: Entirely free support

P5: Yeah, they have a memory, you know, they have support workers who can come and you know give you tips on how you manage the memory and ideas about, you know they have these clocks which are easy to look at, diaries, calendars.
Dementia = memory loss misunderstanding

P8: Now there are issues when you’re diagnosed with this condition.
F8: In this one? Yeah.
P8: Yes. You need to inform DVLA.
F8: Yes. And do we have to have something from you to say that it’s mild or anything?
P8: If they want to write to me, they will write to me.
C8: Hmm mm.
F8: Yes, and can you say it’s mild, can you? Would you say that?
P8: Yes. It is mild. It is mild.
F8: Your memory at the moment.
P8: I will say it’s mild.
P8: But it’s, at the end of the day, it’s their decision. They have doctors there. And they will make a decision based on, you know, all of this.

C8: I’ve got quite a good memory actually.

F8: Yes.

P8: So, I’m not saying that you should stop driving.

F8: No.

C8: No.

P8: But what I will recommend is short distances, familiar routes, with somebody beside you on a nice day when you feel well. You know in the main time, this is generally, we are leaving …. it’s your decision.

C8: But I have no, I have no trouble like if we wanted to go to say to Bournemouth and that. I can remember the route.
F8: I drive as well but I don’t want to take it off him if he as long as he can do it.

P8: Yeah. But why don’t you drive if you are able to?

F8: Well I do. C8: I don’t want her to.

F8: But he, he wants to drive and if he can.

P8: Because I tell you the second implication. Because insurance, you have to inform insurance and that [. . . ]

F8: So it would be better if I drove then?

P8: No, I’m not saying that, you go back, think about it, yeah? And see what you want.

C8: You see, I don’t have any problems remembering routes or going anywhere.

P8: It’s not that. It’s reaction time. That’s where the problem is.

C8: Oh, my reaction time!
2. Language as functional

Used by the professional to:

• Demonstrate s/he has heard the person with dementia/relative but often a rhetorical acknowledgement

• Strengthen a position s/he wishes the person with dementia/relative to take

• Orientate the person with dementia to a preferred expressed emotional state

• Avoid being blamed for bringing bad news (by turning it to good)
Rhetorical attention to alternative explanations

Problems caused by stress?

P7: Now, **what we need to establish is** whether your memory, yes, it’s a memory condition that you’re having that we need to discuss further and address

P7: So, that is what we find in this condition and now I’m going to tell you what it is. It is the early stage of Alzheimer’s. Putting everything together
Emotions talk

P6: Just having a diagnosis of this condition doesn’t mean, you know, you don’t have to feel unhappy.
C6: Well I do feel a bit sad.
P6: Don’t. Don’t. Yes, you will be sad –
C6: Because when I was [. . . ] heavy breathing, I can’t walk fast.
P6: But the condition itself, what is important is you can still live a happy life. That’s what we want, you too! You can still be happy and safe. Two things that I’m asking. Are you happy? Yes, you are, clearly.
Are you safe? And that’s what we want. Yes.
Repeated script of emotions talk

P7: I mean for me I look at two things. I mean are you happy? Are you safe? That’s about it.

C7: Mm

P7: Both boxes ticked fine.
P7: You are happy

C7: Yes

P7: You are safe, at present.
Bringer of good news

P5: And it’s vascular, because of all the changes in the scan and all that.
F5: And the scan is showing that?
P5: So there is a definite memory condition.
F5: Yes.
P5: And we use the term dementia but dementia means memory condition, that’s all it means.
F5: Yes.
P5: It’s not like Alzheimer’s which is the good news.
F5: No. Yes, yes, yes. Good. Good. Well that’s good isn’t it!
C5: Yes.
F5: I mean we didn’t really think it probably would be but you don’t know.
P5: Yeah, it’s not Alzheimer’s
# Summary

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<td>1. Language as constructive</td>
<td>Dementia as a memory condition</td>
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<td>2. Language as functional</td>
<td>Professional using language to appear to demonstrate listening, to orientate the person to a particular emotional state, to avoid being blamed</td>
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<td>3. Language as positioning</td>
<td>Professional positions person with dementia as ill, vulnerable or as having choice</td>
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<td>4. Language as power</td>
<td>Independence is immediately eroded, pastoral power is used</td>
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<td>5. Effects of language</td>
<td>Value not given to utterances of person with dementia</td>
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Implications

• Be aware of the power of language
• Reconsider defining dementia as a memory problem
• Adopt genuine discourse of living well with dementia

• Tell about diagnosis 1:1 initially, to allow more space for the person to take up different subject positions
• Provide a 1:1 opportunity for discussion with a close relative also
Thank you for listening
3. Language as positioning

Professional positions the person with dementia as:
- A patient with progressive disease (medical discourse)
- A frail and vulnerable older person (ageing discourse)
- A person with choice (consumerist position)

Person with dementia:
- Uses ageing discourse to resist diagnosis

Professional positions herself as:
- Guardian of rights of the person with dementia
F7: Erm, I think we need to know everything, the way that it is so that as a family–
P7: As a family?
F7: as a family, so that we can make decisions, based on
P7: It’s not what you want, it’s what mum wants. Yeah, (Client laughs) but that’s what you would like.
F7: That’s what I want. No I don’t know what –
C7: Yes, I think – I think that’s good.
P7: Sure.
F7: You’re happy with that are you?
Ventriloquism

P8: .So what I’m trying to say is it’s not just your age. You can’t say, “I’m getting forgetful because of my age,” so there is definitely a memory condition.

C8: No. Hmm mm.
4. Language as power

- Power of being given the diagnosis of dementia
- Reducing the freedoms of the person
  - independence (e.g. driving)
  - pastoral power (e.g. power of attorney)
P8: Okay. Because there’s something called Power of Attorney. You’ve heard of that isn’t it?
F8: What’s that?

P8: Power of Attorney is ...
C8: Hmm,
P8: If ...
C8: To make decisions for me.
P8: You make, you nominate someone
F8: Yes.
P8: And say that in future if I need someone to handle my finances or make medical decisions ...
C8: I’m quite capable actually.
5. Effects of language

- Value given to professional’s statements
- Devaluation of statements by person with dementia
C8: Mm yes.
F8: Are you fully understanding what’s being said here?
C8: Oh yes darling.

P7: Sometimes it’s too much information (laughs) given all at once, you know, ask me any question you need to while I write this out for you…
F7: But the medication will slow or has a chance in a lot of people of slowing down this condition
C7: I understand that.

F7: So erm I think that to dismiss medication without even, you know thinking about it, is probably a little bit …
P7: Yeah, what I’m going to suggest here is, let’s not push for it today. Because you’re not very happy, but I’m not going to discharge you. I’m going to offer you a further appointment
F7: Okay Okay
P7: in three or four months. You go back, have a chat, look up about it if you want to read. I’ll give you some, you know, websites you can read up.
P7: Okay
C7: Mm.
F8: Yeah, okay.
P8: Come back and see me and if again you say, ‘Doctor, I still don’t want it’ and if you’ve got all the support that you need, fine, then you can get discharged from the clinic. Is that good?
C8: Okay, yes.
F8: That’s a brilliant compromise, yes.
P8: We’ll do that.
F8: Yes, that’s brilliant.
P8: Yeah. I may get told off for doing that you know because our clinics are so busy but it doesn’t matter. It’s what’s best for you.
C8: Mm.
F8: All right
C8: I’ve always felt the same. I don’t like taking any medicines at all.