

Managing Communication in Dementia: A Case Study

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ABSTRACT

This report is part of research concerned with how spousal carers manage communications with their cared-for partners when living with dementia, and how management strategies change as the dementia progresses. Eleven couples were involved in a four-year longitudinal study using semi-structured interviews at home and participant observation within a creative arts programme. This case study focuses upon one interview with one couple, where both partners were present. It is a demonstration of the way that the caring partner negotiated the difficult situation of being interviewed with the disruptive presence of her cared-for partner. It highlights how the caring partner tried to manage the interview to participate in the research. The findings showed how the caring partner divided her time between paying attention to the researcher, as researcher and guest in their house, and to her spouse who was joining in the three-way conversation.

The conversational strategies and amount of time speaking differed between all three participants, with the interviewer struggling to ask pertinent questions. The caring partner reacted to her spouse's comments and questions, but also responded to the interviewer by explaining what she thought was happening when her spouse talked and answered questions. She adopted multiple roles to reassure, give information, and answer questions from her cared-for partner to manage communications. On the other hand, the spouse with dementia interrupted, changed topics, asked questions, and confabulated at length.

There are also implications for using semi-structured interviews, as the situation affected the dynamics within the spousal relationship, and between the interviewer and the caring partner.

Introduction

A case study approach was used to investigate a particular situation – the second interview with the couple, Susan, the spousal carer, and Peter her husband diagnosed with dementia. Case studies are used to investigate real-life situations, and can be exploratory, explanatory, or descriptive (Yin 2018).

My approach was to 'capture the unique character of a ... situation... in its own terms.' (Hammersley et al. 2000) The transcript of the interview formed the data for the case study, although I also had additional data to enable me to understand some aspects. Willig (2013) argues that it is the particular that is of interest rather than generalisable features.

This case study was of intrinsic interest to me.

As researcher during the interview, I felt frustrated as I found Peter's verbal interruptions in the interactions to be disruptive. When I had the transcript of the interview and read it, I felt that I was at the beginning of understanding the process that had occurred. Although not integral to my doctoral research I decided to undertake some sort of analysis of what had happened during the 90 minutes I was with them. I will introduce the couple briefly and then offer a discussion of my findings from an analysis of the interview's content.

Susan and Peter had been married for 46 years. Peter was a gifted engineer and, with Susan, had set up and run a successful company. They also shared competitive ballroom dancing as an interest. Before Peter was diagnosed with dementia, his memory had been poor, with Susan commenting that he used to forget meetings and decisions that had been made. He explained that his mind was on other things, creative problem solving, but with dementia his memory became a significant problem. They were a very hospitable couple, and Peter very sociable, enjoying chatting. Although I had seen them the previous day at a creative workshop, Peter did not recognise me. They kept the tone light-hearted with laughter and jokes throughout the interview in their spacious kitchen over mugs of tea. I also showed them video footage of themselves in a pottery workshop, which they commented upon.

P: Can you remember that, 'cos I can't.

S: Yes, it's when you made that (indicating a tile).

P: I can't remember.

S: It's clay and you flattened it out, and then we were told to make it look like a house, and you put a face on.

P: Ah, eyes and nose and mouth and all creates another me.

S: Is that you?

P: I must have been walking past this grotty house, actually, some old houses.

S: It's difficult to get the colour. It's difficult to get the colour in the mix. (P. hums) ... Well we don't talk much.

A feature of Peter's dementia was his confabulation. Confabulation occurs in some people with dementia. It is seen as a genuine attempt to fill in gaps in memory with narrative that, to the person with dementia, is true. It is not seen as a form of lying. Two different forms of confabulation are described in the literature: spontaneous confabulation; and provoked confabulation. For example, spontaneous confabulation may be generally plausible and involve embellishments of autobiographical details (Metcalf et al, 2007). Provoked confabulation arises from being asked about something in the past, that is when testing memory. Lindholm (2015) suggests that there are plausible/mundane and fantastical/bizarre confabulations. Orlov and Hyden (2006) suggest that, '...confabulations should not be viewed simply as false statement, disconnected from a possible function in the current situation... Rather they should be regarded as meaning – or sense-making processes for the person telling ... them' and supports the person's identity and self-image.

Peter's confabulations were spontaneous, and often had fantastical elements, they were part of the narrative of his life experiences and important to him.

Aim

I wanted to understand what had happened in the interview, and how the content of the interview added to my research into managing communications.

Method

To undertake an analysis I needed to identify what I was interested in finding out. These topics were suggested by the interview transcript after several readings:

- How much each of us contributed to the conversation
- Who asked questions
- Who answered questions
- Topics of conversation and who introduced them

- Politeness and interest in others – Peter
- Exaggerations or confabulations – Peter
- Comments about the situation – Peter
- How communications were managed by Susan

I used lines of talk as the yardstick for quantity, even though the lines varied between single words and complete lines. I went through the interview transcript identifying which of us had spoken, and then identified the type of utterance. These were added to as the analysis progressed. No analysis was undertaken of the raw data produced, other than expressing raw percentages.

Findings

I will discuss the findings under each contributor, initially general contributions, followed by each participant's input. P = Peter, S = Susan, I = interviewer.

Contributions to the conversation

Susan talked most, occupying 47% of lines of talk. Peter came next with 34%, and I contributed 19%.

Interviewer contributions

My contributions comprised encouraging phatic remarks, usually single words (48%) followed by asking questions (23%). This means that most of my contributions were supporting the interview. The remainder of my contributions were answering questions, giving explanations, or making comments.

Peter's contributions to the interview.

Peter dominated the conversation for a third of the time, talking about himself and his experiences. These contributions were not (directly) related to my interview questions. He also asked the most questions, 80 in all, using them for apparently different reasons:

- For clarification

- To change the topic of conversation for example asking me twice if I would like to look round the house as it was up for sale
- Politeness to a guest. For example he asked me twice where I lived, and if I was cold sitting by an open window
- To re-engage in the conversation after a period when he contributed little, or appeared to be preoccupied
- Frequently his questions would appear to be unconnected to previous talk

S: Can you see that's you? [re video-recording]

P: Um?

S: Do you recognise you?

P: Oh, I didn't know there was another me. He's a bit quiet, he doesn't say much [hums]

P: [to interviewer] Where are you living now?

He also made comments which seemed to be unconnected to previous talk but might refer to earlier topics he had raised. For example, when Susan said he had no memory of the events of the past 40 plus years, but she remembered them. He claimed he had been a window cleaner.

S: Clean windows! You don't do our windows actually.

[laughter]

P. The German thing was really sad that was. And eh, I'd just been, I'd just been called, by the firm's director, the highest level that they'd got in this huge estate ... and then, eh, I got off telephone call, and I had to go back home. And, eh, well, then that was it, they never, they never called me again ... completely gone ... It was me mother actually, and she'd, she'd died before I got home. She put, she put the call in, for me to come back, so I did, and eh, by the time I got back home, she was dead.

When not apparently engaged in the interview, he would hum or tap his fingers rhythmically on the table, which Susan found very irritating. Then he would interrupt Susan's account. After Susan had spoken about how she managed to understand better because she had known him for so long, he became aware we were talking about his life and

intervened, for example ‘Is this talking about me then?’ He also said:

P: Was it me you’re thinking of? What’s the big problem? Me? Who’s he getting mixed up?

When asked questions, he usually did not respond, but changed the subject, or asked another question, gave a vague response such as ‘mm’ or ‘er’ responding to only a third of questions on topic. He also complained that he could not hear, referring to his hearing problems 11 times.

P: You’ll have to raise your voice ... or I’ll have to get some megaphones for my ears... It’s nice of you to come and see us. I can’t hear you but I can see you.

And,

S: But sometimes you don’t pick up the drift of the thread do you?

P: Well you’re being very quiet. A quiet talk.

Peter introduced 13 of the 14 new topics, some short lived, but others had extensive coverage and were usually about Peter’s experiences, including interactions with family members, working abroad and his mother dying.

- Working abroad and his mother dying [57 lines]
- Comments on the video-recording of the couple at the pottery workshop [43 lines]
- Climbing a wall [34 lines]
- Interactions with family members [31 lines]
- Peter’s experience at the university [30 lines]

These narratives included confabulations, most of which Susan recognised and could link to actual events. The confabulations increased as the interview went on, and he took over the conversation.

P: Um, I can still picture that as well, I can still

picture the wall.

S: I think this must be about Santa Claus.

P: It was extended up there, the staff had to climb it ... and for some reason it was something that I’d got the hang of ... and I could run up and down this wall like a rabbit and they couldn’t get, they couldn’t get more than one leg going [laughs]. They had to keep one leg on the floor, or they got one leg on and that was as far as they got.

S: Because I know these bits, like, it doesn’t seem as...

P: You’d never have seen me back here then.

S: Bad or worrying

P: I’d have stayed in Germany then.

Peter also demonstrated that he could use complex sentences and nice differences. When I asked him how he talked to Susan:

P: How do I do what?

I: Talk to Susan

P: I ...

I: Do you do it as you used to do it?

P: Probably [laughs]

S: He can’t remember, that’s a good answer [laughter]

P: I don’t think it’s changed very much, do you?

S: You talking to me?

P: No, I’m talking of you.

Peter also commented on what was happening during the interview conversation, for example after Susan reminded him of my research he said: ‘I don’t think we’re communicating very well on that.’

There was an ebb and flow to their contributions, with a pattern of narration of a story or question and answer. When Peter was speaking Susan waited until he paused before speaking. When Susan was speaking, Peter remained relatively silent. There were also occasions when they had a dialogue contributing equally.

Susan’s contributions

Susan spent approximately half her talk responding to Peter, and half responding to my questions or

directed towards me.

Her talk to Peter comprised:

- explaining and describing 39%
- reminding or jogging memory 27%
- answering questions 19%
- jokes, questions, agrees, refutes, brushes off, apologises and supplies word 13%

Susan spent a lot of time explaining and narrating events to him helping him to understand and describing past happenings to him.

S: I'll just explain. Peter, Andrea's doing some research, she's doing research, she's at university, and she's doing some research into communication.

P: Oh, I thought you were thinking of them for nutcases.

S: Well partly that as well [laughs].

Susan said that she had difficulty knowing if he did not hear what she said, or he did not understand, or was not paying attention to what she said. She also had difficulties when he developed fixed ideas or obsessive behaviour, so that her attempts to manage communications using explanations, reasoning, logic, or persuasion often failed. This was also demonstrated in the interview.

S: Like last night he spent two and a half hours counting his money, counting his coins. And asking me what they were, and which coin should go where and he had them all out, he had the pounds out and "I can't spend these" and "I can't spend the others" because I'd happened to say that if you have any old pound notes you need to spend them.

I: Mm.

S: 'Cos in a couple of weeks they're not gonna be legal tender.

P: Who's she?

S: Pardon? I said I happened to mention that the old pound coins wouldn't be legal tender, but at 2 hours I sort of flip. I went and got a bath, didn't I?

P: You've got a splodge on your chin.

Susan also reminded Peter of things or events, or jogged his memory – for example, of a visit from

their daughter. She answered his questions, and indeed all of Peter's questions were answered by Susan or myself, where appropriate.

When Susan was telling me about a couple portrayed in a painting on the wall, this also demonstrated how correcting Peter did not work.

S: He tells everyone about that, saying that they killed each other.

P: They're both dead.

S: They are both dead, but they didn't kill each other. She died of cancer, and he died over a year later in a care home.

P: I think they tried to kill each other.

S: No they didn't, duck.

P: They fought like cat and dog, those two.

S: They did. 'Cos he had Alzheimer's, well.

P: I went down, and they were both dead on the floor. Well.

Sometimes she just gave up, as he would not be persuaded.

P: But they were a bit hard, and then they finished up dead, that was quite odd.

I: We'll all finish up dead though, won't we?

P: Mm.

S: It's like that Doc Martin advert, that trailer for the Doc Martin that's coming back on the telly.

P: It's what?

(S explains)

P: I'm not sure what you're gabbling on about.

S: Oh, never mind.

In addition to these responses to Peter, she responded to me as interviewer by explaining what she thought was happening when they communicated:

- Susan did a lot of explaining
- She had to repeat herself 'on average I say things 3 times'
- She had to be more precise in her use of language
- Logic did not work
- Disagreement did not work
- Factual corrections did not work

- She gave a lot of instructions (not demonstrated during the interview.)

The conversational strategies and amount of time speaking differed between the three participants. Susan reacted to Peter's comments and questions and answered my questions. She adopted multiple roles to humour, reassure, give information, and attend to Peter to manage communications with him. On the other hand, Peter interrupted, changed topics, asked questions, and confabulated at length. The interview demonstrated the difficulties and frustrations experienced by Susan, and her time commitment to Peter.

Discussion

The analysis of the content of the interview transcript was important as it demonstrates the way that Susan negotiated the complex situation of the interview. She tried to manage communications to participate in the research but was divided between interviewer and spouse. She was very considerate of Peter's agency and sociability. But, importantly, it demonstrated *how* they communicated.

Peter demonstrated considerable verbal skills, being able to narrate stories, use conversational rules, while acting as host to me as guest. It became clear that we all had different foci during the conversation. My focus was upon their interactions and Susan's management of communication. Susan's focus was divided, trying to respond to my questions, paying attention to Peter, and making sense of what he said. Peter's focus was on being a host and telling stories about his experiences, often confabulations.

I learned a lot from this analysis. For example, my relative powerlessness in the context of the interview, as Peter took over the 'entertainment' of the guest (myself). I had felt frustrated at the time, but from the analysis it was clear that Susan also found difficulties in managing communications, particularly as she could never be sure that he was listening to her, could not hear her or did not understand what she said. She had identified the

major problems as Peter's memory which was considerable worse than before dementia. But in addition, his confabulations meant that Susan had to deal with a reality that only Peter understood. In her diary, Susan recorded many examples of Peter's fantasy life, which she could not understand. His obsessive behaviour lasted for hours which again Susan found very difficult to live with.

The analysis led me to question whether interviewing them together was the right decision. Nevertheless, it was important in that it demonstrated, however briefly, the problems Susan was experiencing with Peter's verbosity, and some of the ways that she managed communications with him. I wondered whether I should offer to interview Susan alone, as her private diary entries suggested that managing communications with Peter was very difficult when he became obsessive and violent. However, interviewing Susan alone would provide additional pressure on her to find somewhere or someone to care for Peter whilst she was engaged in the interview. This might also have cost implications.

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