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# Epistemics and frontotemporal dementia

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**Abstract**
We explore how patients with the behavioural variant of frontotemporal dementia (bvFTD) display different degrees of understanding when reporting on their experience of being ill. Using the methods of conversation analysis, we examine the video-recordings of bvFTD patients who had participated in clinical follow-up interviews with a doctor. Patient responses to the doctor's questions were analyzed with respect to the action undertaken (i.e., confirmation vs. denial) and the epistemic stance (i.e., certainty vs. uncertainty) that was conveyed. We found that although patient denials of being ill were conveyed with certainty, these patients were unable to elaborate on their denials, thus generating an implication that they are not aware of their illness and its effects on their lives. By contrast, patients who confirmed being ill tended to produce expanded responses that either revealed the patient's primary access to knowledge or the patient's difficulty in understanding the doctor's question.

**Keywords:** conversation analysis, dementia, epistemic stance, frontotemporal dementia, medical discourse

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## Epistemics and Frontotemporal Dementia

The term 'dementia' originates from Latin ("demens") and may be loosely translated as 'out of one's mind'. This reference to the 'mind' generally carries with it the implication that dementia involves some impairment of a person's 'cognitive' abilities. Dementias, however, may appear in a large variety of forms and present with different clinical features that include, but are not limited to, so-called 'cognitive' impairments involving memory or orientation, as is common in Alzheimer's disease or AD (Snowden et al., 2011). For example, the behavioural variant of frontotemporal dementia (bvFTD) offers a very different clinical picture compared to AD and is primarily marked by a progressive decline in social and moral behaviour (Neary et al., 1998; Rascovsky et al., 2011). Although memory impairment may not be prevalent in bvFTD, especially in the early stages of the disease, various deficits in 'cognitive' ability do become present and noticeable. Many patients, for example, are unaware that they have become ill and are largely ignorant of any changes in their behaviour or of the effects that bvFTD is having on them and their caregivers (Neary et al., 1998). bvFTD patients are also considered to be impaired in their capacity to construe an appropriate *theory of mind* (ToM) concerning other's beliefs and intentions and therefore often have great difficulty in understanding or empathizing with another's feelings or point of view (Neary, Snowden & Mann, 2005). Persons with bvFTD, therefore, are gradually stripped of a fundamental human ability that is necessary in creating intersubjective understandings and a social world in common with others.

Conversation analysts have argued that there are certain *epistemic domains* or *territories of knowledge* to which persons have primary rights and access (Heritage, 2012a; Stivers & Rossano, 2010). For example, knowledge pertaining to first-hand experience such as "how I feel", "what I did the previous day", or "my reasons for doing X" – characterized by Pomerantz' (1980) as Type 1 knowables – is generally considered to be more accessible to the one who had the experience. According to Heritage (2012a), access to any given epistemic domain tends to fall along an epistemic gradient, ranging from shallow to steep, in which someone may have more knowledge with respect to some other. This relative positioning with respect to knowledge (i.e., as being more or less knowledgeable) is referred to as *epistemic status* (Heritage, 2012a, 2012b). Within face-to-face interaction, however, persons may design their turns at talk to appear congruent with their epistemic status or, alternatively, to modify or even challenge an assumption that their relative rights or access to a certain epistemic domain is higher or lower. For any given turn at talk, the interactional and lexico-grammatical features that speakers make use of to display knowledge – as, for example, modal ("certainly", "possibly") and evidential

("I heard that…") expressions – form what is called an *epistemic stance* (Heritage, 2012a, 2012b).

This basic competence, in which persons are able to display specialized access to epistemic domains that involve their life circumstances, gradually becomes undermined for persons with bvFTD; that is, they mostly seem unaware of being ill, of how the dementia is influencing their life and of how others may be perceiving these changes. Further, they begin to engage in behaviours that show a blatant disregard for others. These changes in character eventually give others the impression that they have become non-empathic or even 'sociopathic' (Mendez, Chen, Shapira, & Miller, 2005). Nonetheless, the general questions of how bvFTD patients display a lack of awareness of their illness (or of the various circumstances surrounding their illness) and how patient awareness/ non-awareness emerges in and through sequences of talk has remained virtually unexplored. In order to address these issues involving patient awareness, we examine clinical follow-up interviews between doctors and bvFTD patients, by drawing form the epistemic concepts outlined in Heritage (2012a, 2012b): Territory of knowledge, Epistemic Status and Epistemic Stance. By focussing on question/ answer sequences in which patients respond to the doctor's questions on the topic of the patient's illness, we explore the following questions:

1) Which epistemic stances – in terms of the certainty vs. uncertainty of being ill or healthy – are conveyed in the patients' responses?
2) How are patient responses that deny or affirm their illness - and the epistemic stances realized therein – more or less indicative of a lack of awareness and why?
3) How does the doctor display her understanding of the patient's response (i.e., as an appropriate versus 'problematic' response) and how does this understanding emerge within an interactional sequence?

## Background on bvFTD

bvFTD is a neurodegenerative disorder that is marked by atrophy of the brain's frontal and/or anterior temporal lobe. It is estimated that bvFTD accounts for up to 20% of all presenile dementia cases (Snowden et al., 2002). Studies have also suggested that, for middle-aged persons, bvFTD may be just as prevalent as AD (Mendez, Chen, Shapira, Lu, & Miller, 2006). bvFTD affects men and women equally and generally begins between the ages of 45-64, although cases have been reported for persons as young as 21 and as old as 85 years. There is currently no available cure for bvFTD. The mean duration of the illness, from onset until death

is 6-8 years, but rapid progression may also occur (i.e., within 2 years). Associated illnesses, such as motor neuron diseases, tend to accelerate the course of the illness. According to Neary et al. (1998), bvFTD is but one subtype of what they have termed frontotemporal lobar degeneration (FTLD). Three sub-types of FTLD have been identified as: 1) Frontotemporal Dementia (bvFTD); 2) Semantic Dementia (SD); and 3) Progressive non-fluent aphasia (PNFA). bvFTD is characterized by profound changes to an individual's personality and to disordered social conduct. SD and PNFA patients, on the other hand, reveal distinct problems in language processing (Ash et al., 2006; Peelle & Grossman, 2008). In SD, semantic processing is impaired, whereas in PNFA, patients display agrammatic and disfluent speech.

## Conversation analysis and talk in clinical settings

Conversation analysis (CA) is the study of social interaction in everyday and institutional contexts and gives due consideration to how displays of understanding emerge through the coordinated accomplishment of sequentially ordered actions between conversational participants (Atkinson & Heritage, 1984; Drew & Heritage, 1992; Heritage, 1984; Sacks, 1992; Schegloff 2007). Over the years, CA research has elucidated many facets of talk in clinical settings such as how medical consultations are interactively structured (Robinson, 2003), how doctors present "bad news" to patients (Maynard, 2003), how patients account for their visit (Heritage & Robinson, 2006), how patients resist certain treatments (Stivers, 2005), and so on (for an overview of some of the more relevant CA studies on talk in medical contexts see Heritage & Maynard, 2006). Other research has focused on exploring medical disorders, mostly neurological, that negatively impinge on a person's communicative abilities (for a concise overview see Garcia, 2012). For example, much attention has already been given to aphasia (Goodwin 1995; Wilkinson, Bryan, Lock, & Sage, 2010), Autism Spectrum Disorder (Maynard 2005; Stribling et al. 2007, 2009) and persons with intellectual disabilities (Antaki, Young, & Finlay, 2002; Antaki, Finlay, Walton, & Pate, 2008). CA work on dementia, however, is just beginning to flourish. A recent edited book by Mates, Mikesell and Smith (2010) contains a number of case studies that use CA methods to explore the various ways in which interactions with FTLD speakers deviate from so-called 'typical' ones and to explain how these atypical interactions may result from common clinical features of FTLD.

## Understanding and epistemics

The notion of *awareness* or *understanding* being developed in this paper draws primarily from CA. In its most general form, understanding is taken as an interactional accomplishment that emerges in and through sequences of talk (Heritage, 1984; Mondada, 2011). Thus, when a first speaker asks a question and second speaker responds, the response will reveal the speaker's understanding of the question (i.e., what the question was aiming at) or perhaps even the speaker's difficulty or failure to understand (Schegloff & Sacks, 1973). Different formulations of a response may also reveal different benchmarks or depths of understanding. Sacks (1992, p. 252), for instance, argued that whereas some responses actually *demonstrate* understanding of a prior action, other responses only *claim* understanding. As Sacks has argued, someone who utters "I agree" after someone else has given an opinion may only be said to be 'claiming agreement'. In order to show or demonstrate agreement, one needs to perform a discursive 'operation' on the opinion; for example, by more cohesively tying one's turn to the prior one, as in "I've also made a similar argument in my article…" Thus, in many sequential environments, mere responses of "yeah", "no", "uh huh" may be deemed insufficient to really show the prior speaker that the respondent has grasped the import of what has just been said. An expanded turn, however, one that extends beyond a mere "yes" or "no" and seeks to engage with the content of the prior action, would be deemed much more successful at showing understanding.

Responses may also demonstrate understanding in different and important ways. A recent study by Avineri (2010) has suggested that bvFTD patients may display different degrees of awareness that they are ill or that they have undergone changes due to their illness. By examining clinical interviews with bvFTD patients, Avineri provided an example in which a patient showed some awareness that her family members may have noted changes in the patient's character. Although the patient initially denied that she has changed in any way over the past ten years, when questioned further by a doctor, the patient eventually turned to her daughter who was co-present in the room to solicit her view (e.g., "do you see me as different?"). Thus, although the patient displayed a lack of awareness in terms of how bvFTD has influenced her character, she was able to display some awareness that her daughter might think differently and, by implication, that she might have changed after all.

Understanding and knowledge are intimately linked to each other, because by displaying your understanding to a prior speaker, you ultimately communicate what you know and how you know it. A display of knowledge may thus be used as a resource by next speaker to ascertain how well the respondent has understood.

Knowledge, as it is interactively constituted through talk, has been taken up in CA under the general rubric of *epistemics* (Heritage, 2012a, 2012b). Heritage identifies three concepts that are central to epistemics: 1) Territories of knowledge; 2) Epistemic Status; and 3) Epistemic Stance. The notion of territories of knowledge first gained some prominence in linguistics through Labov and Fanshel's (1977) distinction between A-events and B-events. For A-events, certain information is known to A, but not to B and for B-events, the reverse holds. Through this conceptualization, they were able to explain how declarative clauses could function as B-events that seek information (e.g., "you've been taking your medicine.") rather than A-events that assert information. A few years later, Pomerantz (1980) provided a related view by distinguishing between Type 1 and Type 2 knowables: The former refers to knowledge derived from first-hand experience, whereas the latter refers to knowledge that is indirectly acquired as through reports or inference. Furthermore, Type 1 knowables have a strong moral component and thus come with certain responsibilities (Stivers, Mondada & Steensig, 2011); for example, we may be held accountable for not knowing or forgetting information related to our personal biographies such as where we were last night or our current state of health. Furthermore, an explicit lack of knowledge pertaining to one's illness, as is often the case with bvFTD patients, may generate certain kinds of inferences such that one is no longer 'fully' cognizant and that one has somehow 'lost' access to an important epistemic domain.

Epistemic status refers to the gradient – as more or less knowledgeable – that persons may occupy with respect to a certain epistemic domain. It is important to mention that this gradient is in no way static but may be in a constant state of flux. As Heritage (2012a, p. 4) puts it, "the epistemic status of each person, relative to others, will of course tend to vary from domain to domain, as well as over time, and can be altered from moment to moment as a result of specific interactional contributions." With respect to doctor-patient interactions, although the patient is more knowledgeable about his or her symptoms than the doctor, by conveying these symptoms, the doctor becomes more knowledgeable concerning this epistemic domain (i.e., patient's symptoms with regard to sickness), thus evening out the epistemic gradient between the two.

The final concept addressed here, *epistemic stance*, refers to the interactional means through which speakers convey their knowledge. Thus when designing their turn at talk, speakers construct an epistemic stance, often drawing from epistemic resources such as modal or evidential expressions to express varying degrees of certainty or uncertainty. Further, it is through a speaker's construction of epistemic stance that epistemic gradients may become reconstituted and renegotiated (i.e., locally managed) through turns at talk (Heritage & Raymond, 2005). In this

way, a speaker who makes a display of knowledge about a topic may be trumped by a next speaker who is able to demonstrate even greater knowledge – and, by implication, show that the prior speaker may have been misinformed.

## Data and Method

Seven patients, four women and three men, diagnosed with bvFTD at a hospital in Austria have participated in this study.[1] Patient age ranged between fifty-six and eighty-three. All patients had previously received the diagnosis of bvFTD from the hospital in which the study was undertaken and consent was provided for them to take part in regular neurological tests at the hospital (e.g., MRI). As a component of this study, patients agreed to take part in routine clinical follow-up interviews with a neurologist in various settings (home, senior citizen home, hospital clinic) in which caregivers were mostly but not always present. The interview oriented to the general aims of 'history taking' in which information about the patients' general life situation, which included whether they were aware that they were ill and if they or their immediate family had any illness-related concerns, was elicited by a neurologist. All interviews were video-taped and transcribed using the transcript notation developed by Jefferson (2004) (see Appendix for a summary of the transcription conventions used in this paper). The neurologist who conducted the interviews was female and had prior knowledge of the patients' diagnoses. The doctor also had prior contact with some but not all of the patients. All examples used in this paper contain English translations from the original German. The analysis of the interaction is made possible and reliable from the direct comparison between the original German text, the literal translation and the fluent English one. Identifying information was removed from the transcriptions and patients, when referred to, were given pseudonyms.

Interviews were analyzed by taking full account of the epistemic stances of speaker utterances. In adopting a CA perspective, epistemic stances were analyzed according to a range of grammatical and interactional phenomena such as epistemic modality (e.g., might, certainly), evidentiality (apparently, seems), clause mood (declarative, interrogative), discourse markers (e.g., "oh") and non-verbal (i.e., gesture, bodily actions) expressions (Heritage & Raymond, 2005; Heritage, 2012a). Because the interviews were composed of a string of question/response (Q/R) sequences, this adjacency pair sequence became our focus of investigation. In order to examine how patients construct an epistemic stance and display an awareness to what is being asked, we drew from Heritage's (2010) work on Q/R se-

quences in clinical interviews. Heritage (2010, p. 44) argued that questions set up specific constraints, as shown in Table 1; that is, questions set topical agendas, embody presuppositions, convey epistemic stance and incorporate preferences. Thus, when responding, patients must orient to these aspects of the question either by confirming or aligning with these constraints or by disconfirming or disaligning with them. Consider, for example, the following question directed to a patient: "Is your illness causing you some problems?" This question not only sets up a topical agenda in which the patient's illness-related problems may be discussed, but it also presupposes that the patient has an illness. Further, the question is information seeking and places the patient in a position of having primary rights and access to provide the information. Lastly, the question is designed to receive a 'preferred' "yes" response.

Table 1. *Dimensions of Questioning and Answering (adapted from Heritage, 2010, p. 44)*

| Physician Questions | Patient Responses |
|---|---|
| Set topical agendas | Conforms/ does not conform with topical agendas |
| Embody presuppositions | confirm/ disconfirm presuppositions |
| Convey epistemic stance | display congruent/ incongruent epistemic stance |
| Incorporate preferences | align/ disalign with preferences |

Through the lens of Heritage's Q/R framework, it becomes possible to show how patients may perform various kinds of discursive work when responding and, more importantly for our paper, it illustrates the ways in which patients position themselves with respect to a certain epistemic domain and, additionally, how they display an awareness of their illness. To provide an example, let us return to the prior physician's question mentioned above: A detailed response outlining a number of illness-related problems would not only index the patient's epistemic primacy in terms of rights and access to know about the illness's effects, but would also demonstrate the depth of understanding of how the illness is affecting the patient's life. An unexpanded denial such as "no" or even an "I don't know", however, would also have epistemic relevance and implications for the patient's aware-

ness. For the former response, 'certain' knowledge that the illness is not having an affect would be conveyed and, for the latter, the patient would be claiming uncertain knowledge. Regarding patient awareness, the unexpanded "no" may be indexing limited awareness as the patient fails to account for why the illness does not exhibit any negative influences, whereas the "I don't know" would be explicitly conveying non-awareness. Thus, by examining Q/R sequences in this way, insight into each patient's epistemic stance (i.e., what bvFTD patients know, how they know it and the degree of certainty in which they claim to know) and their display of awareness concerning own illness and the effects of the illness on their lives may be obtained.

## Analysis

Being a competent social actor implies having epistemic authority over your own personal biography (Pomerantz 1980). This means that people are generally able to account for their own past and present actions and to provide a wide range of information that pertains to themselves. Major illnesses such as dementia form a part of everyday life and the effects that dementia has on persons can be very striking. For bvFTD, persons show a decline in interpersonal conduct (e.g., decline in manners and decorum and increased sexual behaviour), impaired regulation in interpersonal conduct (e.g., laughing and singing in inappropriate contexts) and a loss of empathy or moral emotions (Neary et al. 1998). But what is even more striking is that persons with bvFTD tend not to be aware that these changes have occurred or even that they have an illness. And further, our understanding of how persons with bvFTD display unawareness or a lack of knowledge in 'real-life' contexts is still under-developed.

In this section, we explore how bvFTD patient responses relate to their degree of awareness of being ill by examining how patients report on their illness when questioned by a physician. It was found that the majority of patients denied having an illness and/or denied that the illness was a concern to them. These patients also conveyed an epistemic stance of high certainty in which their denials tended to be unmitigated and produced in overlap with the question. Differences were found in two of the patients. One patient confirmed that he had an illness, whereas the other, although admitting to being ill, displayed uncertainty with regard to what the doctor's question was targeting. Both patients also provided more elaborated responses: For the patient who expressed explicit confirmation, this worked to por-

tray himself as more knowledgeable; For the uncertain patient, this worked to further illustrate his lack of understanding.

## Denying illness or concerns

bvFTD patients tended to deny that they had an illness or that they were concerned about their illness. For the most part, patient denials were realized as unexpanded versions of "no"; that is, although the doctor's questions tended to seek confirmation of the illness, the patient's denial did not contain an account that explained why confirmation could not be given. Consider Example 1 (Doc=doctor; Pat=patient):

Example 1. *Mrs. Meierhofer*

| | | |
|---|---|---|
| 01 | Doc: | *Frau Meierhofer? .hh [was ham's denn für eine krankheit.*<br>what have you then for an illness<br>Mrs. Meierhofer? what kind of illness do you have. |
| 02 | Pat: | *[joh*<br>((P is preoccupied with filling out a form ---------->)) |
| 03 | | (1.0)<br>((P continues filling out form)) |
| 04 | Doc: | *w- wissen's des genau.*<br>know you that exactly<br>d- do you know that exactly.<br>((P continues filling out form)) |
| 05 | | (1.8)<br>((P returns pen to doctor)) |
| 06 | Pat: | *na:. hab i ned.*<br>no have I not.<br>no:. I don't have anything. |
| 07 | | (0.7) |
| 08 | Doc: | *↶fühl'n sie sich krank.*<br>feel you REFL ill<br>do you feel ill. |
| 09 | Pat: | *na:(h):.*<br>no |

| | | |
|---|---|---|
| 10 | | (2.5) |
| 11 | Doc: | *gar ned. sans [ganz::*<br>at all not are you completely<br>not at all. are you completey |
| 12 | Pat: | *[na: i bin ganz g'sund.*<br>no I am completely healthy |

To begin, the doctor asks a wh-question that seeks information on what illness the patient has. The question, therefore, presupposes that the patient is ill and that the patient can adopt epistemic rights and access in order to provide the information. After a 1-sec pause in which the patient does not answer, however, the doctor reformulates her question in line 04 by explicitly addressing the patient's "exact" state of knowledge ("*wissen's des genau*"); that is, the question no longer presupposes the patient's knowledge of her illness and now opens up the possibility that she may not have sufficient access to this epistemic domain. Following the question in 04 is another even longer pause during which the patient returns the pen to the doctor. We would note that during lines 01-05 in which the doctor poses two questions in series, the patient is engaging in the concurrent activity of filling out a consent form. Thus, the patient's delays in responding or 'no-responses' (i.e., the pauses intervening between the doctor's questions and the patient's eventual response) may not so much be expressing disaffiliation or a difficulty with answering the question, but rather an inability to engage in both activities (i.e., filling out a form and answering) simultaneously.

The patient then answers in line 06 by ignoring the reformulated question and orients back to the doctor's initial question by directly denying the presupposition that she is ill. Now if the doctor had merely been seeking information or had accepted the patient's view, we might have expected a *sequence closing third* (SCT) move such as "oh" or "okay" (Schegloff 2007) to signal that the information has been received. But, these possible 'nexts' are not produced and, instead, the doctor remains on topic in 08 with a reformulated question that no longer orients to the patient's illness and what she knows ("*wissen's*") and that instead focuses on how she experiences (i.e., feels) her state of health more generally ("*fühl'n*"). But even here the patient responds by denying that she feels ill. This leads the doctor to produce a revised version of the patient's denial ("*gar ned*") and then a request for confirmation in 11. Although the doctor's response appears to be affiliating with the patient's prior turn, we argue that this is not so for two reasons: First, affiliation tends to be produced contiguously (i.e., quickly), but the doctor waits 2.5-s before responding and second, the doctor partially *mirrors* (Ferrara, 1994, p. 118)

and also upgrades the patient's prior denial of "*na:(h):*", which we believe is functioning to get the patient to 're-think' and elaborate on her answer. The patient, however, seems to orient to the doctor's turn as affiliating and, thus, proceeds to assert that she is completely healthy ("*ganz g'sund*").

The above example has shown how a patient resists the doctor's presupposition that she is ill. Patients may, however, accept the presupposition that they are ill, while denying that the illness has any negative implications. Consider Example 2:

Example 2. *Maier*

| | | |
|---|---|---|
| 01 | Doc: | *Frau Maier. i hab a paar fra:gen an sie*<br>Missus Maier. I have a couple questions for you |
| 02 | | *.hh wie is des mit der er<krankung>.*<br>how is it with the ill<ness>.<br>how is the ill<ness> |
| 03 | | *mocht inna die große ↶sorgen [oder*<br>makes you that big concerns [or<br>does that give you a lot of concern [or |
| 04 | Pat: | *[nah.*<br>[no.<br>*P: horizontal nod* |
| 05 | Doc: | *ned.*<br>not.<br>*D: horizontal nods*<br>*P: horizontal nods* |
| 06 | | (1.8)<br>*P: horizontal nods* |
| 07 | Doc: | *wie kommen's damit zu↶recht*<br>how come you with this manage<br>how do you cope with that |
| 08 | | (2.0) |
| 09 | Pat: | *gut. guat.*<br>good. good.<br>*P: nods* |

The doctor begins this sequence by asking two questions in series; a wh-question followed by a Y/N interrogative. Here also, the questions presuppose that the patient has an illness; that is, following the doctor's Y/N interrogative question in line 03 ("*mocht inna die große ↶sorgen oder*"), either a *type conforming* "yes" or "no" response (Raymond, 2003) from the patient would implicitly confirm that she has an illness. The patient orients to the Y/N interrogative by providing a type-conforming "nah". Thus, it is not the presupposition that is denied, but the proposition that she has concerns. Her denial is also strengthened non-verbally through her repeated horizontal head movements or nods. Now given that the patient has tacitly confirmed that she has an illness, there is an implication that the illness causes some forms of hardship for the patient and may introduce a number of changes in the patient's prior everyday life routines; that is, although the patient may not have concerns, she may want to mention the ways in which the illness has made it more difficult for her to navigate through life. For this reason, the patient's "nah" in line 04 may appear 'minimal' and warrant some form of further expansion and/or account. That more talk is expected from the patient can be seen from the subsequent interaction. In line 05, the doctor begins by repeating the patient's prior denial and then by withholding from speaking. This interactional practice has been found to work as an implicit prompt for the addressee to produce more talk (Muntigl & Hadic Zabala, 2008). But as no further talk is forthcoming, the doctor then utters a follow-up question that specifically addresses the patient's possible difficulties with the illness ("*wie kommen's damit zu↶recht*"). By continuing within the general topic of the patient's illness-related concerns and troubles, more expanded talk on the patient's coping strategies becomes relevant. But here again, the patient provides a minimal response in 09 that merely affirms her ability to manage her illness, while simultaneously denying the implication that, for her, coping entails any hardships.

Examples 1-2 have shown how patients provide answers to doctor's questions that deny the presupposition that they are ill or deny any implications that the illness is affecting them adversely. Patient denials are conveyed directly, in a non-hesitant manner and without epistemic expressions that work to downgrade the patient's epistemic primacy. Thus, the turn formats of both patients function to position them as certain in the knowledge that they are healthy individuals whose lives have not changed in the least. This certainty, however, stands in marked contrast to the doctor's orientation to their responses and to the interactional requirements placed on the patients. In the former, doctors tend to treat the patients' responses as unexpanded and as needing further elaboration. This orientation is conveyed by the doctor through her use of mirroring repeats, pauses and

follow-up questions. In the latter, the patient's direct and unelaborated denial seems to resist the interactional requirement or expectation to expand on (e.g., provide an account for) one's 'dispreferred' response (Pomerantz, 1984; Schegloff, 2007). For this reason, the patient's 'minimal' response works merely to *claim* rather than *demonstrate* understanding (Sacks, 1992, p. 252). In this way, the patient's display of certainty does not really square with the patient's understanding of their illness and nor with the results of various medical tests and to family members' perceptions. A show of knowledge that one is really healthy and not ill would have required something other than a minimal denial. For example, the patients could have provided an account that provides evidence for their good health. Or, they could even have combatted the assumption that they are ill, by arguing that the doctors and caregivers have somehow been mislead. Thus, because the patients do not volunteer additional information, this influences the effectiveness with which they report their own experience. Although these patients have certainly shown that they can make relevant interactional contributions by providing appropriate answers, it would seem that these patients fail to grasp what is actually at stake in these interviews; that is, a doctor is trying to get patients to elaborate on how the illness is affecting their lives and those of family members, but these patients do not seem at all concerned about why the doctor is trying to do this, especially given that they claim to be in good health. Indeed, these patients do not seem to operate under the assumption that they should in any way defend themselves from possible negative assessments that they are unaware of being sick and hence unable to manage their own lives. Their minimal responses demonstrate that they are not aware of the seriousness of the presupposition the doctor's questions convey.

## Affirming one's illness

**Conveying certainty**. One patient did not deny, but rather affirmed that he was ill and that the illness created worry and problems. Through his slightly expanded responses to the doctor's questions, this patient was not only able to express certainty that he was ill, but also that he had an elaborated understanding of the effects that his illness was having on him and his family. This patient had a mixed dementia bvFTD/PSP. Because of this, the patient had great difficulty in speaking and spoke very slowly. Consider Example 3:

Example 3. *Zingler*

| | | |
|---|---|---|
| 01 | Doc: | .hh m: macht inna diese Krankheit ↺sorgen. (1.0) Herr Zingler.<br>m: makes you this illness concerns. Mister Zingler<br>d: does this illness cause you worry. (1.0) Mister Zingler. |
| 02 | Pat: | *j::o:h. macht ma ↑scho sorgen. .hh u- und wa:: w::: (1.0)*<br>yes makes me definitely worry. a- and wa w<br>yes definitely makes me worry. a- and wa:: w::: |
| 03 | | *(oiwei) °macht ma° .hh ma: ↺sorgen.=*<br>always makes me .hh me worry. |
| 04 | Doc: | *=was macht inna da sorgen. speziell jetzt*<br>what makes you here worry. especially now<br>what makes you worry here. especially now |
| 05 | Pat: | *u:: [bitte.*<br>u:: [pardon. |
| 06 | Doc: | *[is es eher des ge::h'n [oder das reden oder*<br>[is it more the walking or the talking or |
| 07 | Pat: | *[a:::::::::::::::::::::::: h::::m* |
| 08 | Pat: | *<das nicht aufsteh'n und das reden>*<br>the not getting up and the talking<br>not getting up and talking |
| 09 | Doc: | *°j::a::.° ich weiß.*<br>yes I know.<br>*D: nods* |
| 10 | Doc: | *.hh ham's des g'vüh das sie die angehörigen*<br>have you the feeling that they the immediate family<br>do you have the feeling that they the immediate family<br><br>*oiso ihre gattin a sorgen macht.*<br>I mean your wife also worry makes<br>I mean your wife also has concerns |
| 11 | Pat: | *oh joh. hhh*<br>oh yes<br>*P: nods* |
| 12 | Doc: | *joh. okay.*<br>yes. okay.<br>*D: nods* |

The doctor begins with a Y/N interrogative that presupposes the patient's illness and that seeks confirmation about whether the patient has worries. In 02, The patient responds with a confirmation ("*j::o:h*") and then expands on his answer by repeating some of the 'content' of the doctor's question ("*macht ma sorgen*"). Note also these repetitions become modified in important ways through the modal expressions "definitely" ("↑*scho*") and "always" ("*oiwei*"). By adding these expressions, the patient is able to vie for greater *epistemic rights and access* (Heritage & Raymond, 2005) in talking about his concerns. After having received upgraded confirmation from the patient, the doctor then proceeds in 03 to explore the causes of the patient's concerns by asking another question. What then follows are near simultaneous turn selections by both the patient and the doctor. While the patient responds by initiating repair with "*u:: bitte.*" (Schegloff, Jefferson & Sacks, 1977), the doctor expands on her question by providing candidate reasons for his concerns. During the doctor's expansion in line 06, the patient makes a bid to select next turn (line 07) but is unable to articulate a word. In the next turn, however, the patient responds by confirming one of the candidate reasons proposed by the doctor ("*das reden*") and by providing an alternative reason ("*das nicht aufsteh'n"*). Here again, the patient does not merely confirm or repeat the doctor's candidate reasons, which would have simply been viewed as claiming knowledge. Instead, by adding alternative information, he demonstrates that he is able to draw from his biographical (Type 1) knowledge. It should be noted that the response shows certainty (awareness) of the PSP-related illness (i.e., not getting up and talking), but no direct awareness of the bvFTD-specific cognitive deficits. Later on in the interview, however, the patient did confirm that his personality has become altered, thus displaying some awareness of the changes induced by bvFTD.

In line 09, the doctor responds empathically ("*°j::a::.° ich weiß.*"), which seems to close the prior sequence, and begins a new sequence by asking the patient if his wife also has concerns. The patient then provides intensified confirmation with the addition of an emphatic "oh". Heritage and Raymond (2005) have argued that these emphatic devices work to upgrade the speaker's epistemic rights and access. Thus, although the patient has not *demonstrated* knowledge in this sequence in a highly elaborated form, he has made a strengthened claim to confirm that his wife also has concerns about his welfare. The doctor then utters the SCT ("okay") that displays acceptance of the patient's viewpoint (Beach, 1993).

When questioned by the doctor about his illness, this patient made numerous displays of certainty by employing modal expressions of certainty (line 02), adding alternative, Type 1 information (line 08) and prefacing confirmation with an em-

phatic "oh" (line 11). But in contrast to the patients shown in examples 1-2, this patient did more than claim understanding; he was able to demonstrate it as well by modifying his confirmation to reveal his epistemic access of his unique biographical knowledge. We would also point out that the doctor responded much differently to this patient. Here, she would provide SCTs that display acceptance of the patient's knowledge displays and would also display understanding and empathy with the client's position. For the other patients, by contrast, the doctor would reformulate her questions and use prompts to elicit a 'different', or more elaborated, response from the patient, presumably one that displays some understanding of their illness.

**Conveying uncertainty.** One of the patients displayed a degree of difficulty in understanding the import of the doctor's questions. These responses from the patient ultimately conveyed uncertain knowledge with regard to his direct experience and understanding of his illness. Consider Example 4:

Example 4. *Schadinger*

| | | |
|---|---|---|
| 01 | Doc: | *sagen sie die: krankheit beeinträchtigt sie die ↑sehr.*<br>tell me the illness (negatively) affects you it a lot<br>tell me the illness does it (negatively) affect you a lot. |
| 02 | | (1.3) |
| 03 | Doc: | *[die weswegen sie im ((name of hospital)) san.*<br>the one why you in ((name of hospital)) are.<br>the one because of which you are in ((name of hospital)) |
| 04 | Pat: | *[najo:h.*<br>we:ll.<br>*D: slight head shake* |
| 05 | | (0.9) |
| 06 | Pat: | *hm?* |
| 07 | Doc: | *die- diese kra:nkheit weswegen sie: im ((name of hospital)) san.*<br>thi- this illness why you in ((name of hospital)) are.<br>thi- this illness for which you are in ((name of hospital)) |
| 08 | | *beeinträchtigt sie die sehr.*<br>(negatively) affects you it a lot<br>does it (negatively) affect you a lot. |

| | | |
|---|---|---|
| 09 | | (1.0) |
| 10 | Pat: | *najoh*<br>well<br>*D: slight head shake* |
| 11 | | (1.2) |
| 12 | Pat: | *jetzt b- ((clears throat)) mit'n gehen hat's es hoit oiweil. [.hh heh.*<br>now w- with the walking has it just always<br>now w- ((clears throat)) with walking its just always a problem |
| 13 | Doc: | *[mit gehen*<br>[with walking |
| 14 | Doc: | *und was is mit'n gedächtnis. is da ois:- da ois:*<br>and what is with the memory. is there everything- there everything<br>and what about memory. is everything- everything |
| 15 | Pat: | *jo:h des geht so hoibwegs.*<br>yes that goes like to some extent. |
| 16 | Doc: | *da passt eigentlich [ois.*<br>here fits actually everything<br>everything is fine actually. |
| 17 | Pat: | *[mm hm.* |

At the beginning of this example, the doctor formulates a Y/N interrogative that presupposes the patient's illness. Following 'no response' from the patient during a 1.3sec pause, the doctor in line 03 works to unpack her prior turn by more clearly specifying that she is referring to the illness for which he is receiving treatment at the hospital. The patient simultaneously begins his turn with the doctor in 04, producing a verbal "*najo:h*" ("well") and a non-verbal head shake. Schegloff and Lerner's (2009) recent analysis of "well" in turn-initial position has shown that this discourse marker tends to signal the speaker's non-straightforwardness in responding. 'Non-straightforwardness' is often realized as impending disaffiliation (on the part of the respondent) or, more generally, that the provision of an appropriate 'answer' will be met with some difficulty. The patient's difficulty with responding and with understanding the import of the doctor's question seems to intensify in lines 05-06 when the patient remains silent for another 0.9sec and then initiates repair with "hm?". Further, the repair initiation may also be conveying that he has failed to understand the doctor's elaboration from line 03. The doctor then addresses the patient's repair initiation by reformulating her question in 07-08, while keeping the content nearly identical. The patient, however, again evinces

difficulty with the question, as evidenced by the 1-sec pause in line 09, followed by another turn-initial "*najoh*" and another pause of 1.2-sec. Although the patient does eventually provide a response in line 12, it seems to fail to make coherent and relevant ties with the doctor's question. First, the answer seems to be designed to respond to a more everyday question that targets the patient's general state of health, rather than to a question that seeks specific information regarding his bvFTD-related illness; that is, the response "*mit'n gehen hat's es hoit oiweil*" ("with walking its just always a problem") focuses on his 'usual' and 'everyday' ailments and does not flag symptoms or effects that are in some way specialized or exceptional. Second, his difficulty with walking is not formulated as an ailment that warrants specialized treatment in a hospital. Thus, the inference drawn from the patient's response is most likely that the patient's problem with walking is a result of his advancing age – he was 83 at the time of the interview – rather than a manifestation of bvFTD.

In line 13, the doctor then provides a confirmatory prompt ("*mit gehen*") that could potentially initiate another sequence of talk and more elaboration from the patient, but then immediately changes the topic to his memory. This shift of topic to memory could have been motivated by the patient's prior response; that is, because the patient was unable to clearly indicate an understanding that he was receiving treatment at a hospital for bvFTD and that bvFTD comes with certain symptoms and effects that do not involve difficulties in walking, it is possible that the patient's memory has also become impaired. The patient's response to the doctor's question in line 15 is noncommittal, using the expression "*so hoibwegs*" ("like to some extent") to considerably downgrade the epistemic strength with which he asserts his memory capacity. The doctor then utters a request for confirmation that everything is fine with the patient, to which he responds with weak acknowledgement ("*mm hm*").

The turn formats of the patient's responses repeatedly showed that he had difficulty in responding to the doctor's questions. This difficulty was realized through his use of "well", repair initiation and his numerous delays in responding. Further, when he did provide a response, not knowledge but *unawareness* was demonstrated. What the patient showed was that he did not know why he was being treated in a hospital and that he understood his illness as 'typical' old-age ailments such as having difficulty walking. Thus, in contrast to the other patients, who were able to deny or affirm their illness in a fairly direct and straightforward manner, this patient's non-straightforwardness in responding seemed also to index a degree of uncertainty in which he was not entirely confident about what was being asked of him.

## Conclusions

Asymmetries in epistemic status have been argued to play a pivotal role in enabling social interaction. Heritage (2012b), for example, speaks of an "epistemic engine" in which imbalances of information between speakers work to propel the speakers into sequences of talk that become closed off once the imbalance has been compensated. In a similar vein, Enfield (2006, p. 399) argues that an "*informational imperative* compels individuals to cooperate with their interactional partners in maintaining a common referential understanding, mutually calibrated at each step of an interaction's progression." The clinical follow-up interviews between bvFTD patients and a doctor were marked by imbalances of information of two different orders. On the one hand, the doctor lacked information concerning the specific effects that the illness had on the patient and his or her immediate family. This imbalance worked to propel the interaction forward, as seen through the doctor's repeated attempts to gain some information on this topic. On the other hand, the doctor and some of the patients (from examples 1, 2 and 4) seemed to have competing views of the patient's state of health: There was the doctor's knowledge that the patients had a confirmed diagnosis of bvFTD versus the patients' display of certainty that they were not ill or that their illness was not causing them any concern. Thus, the doctor's attempts at opening up the sequence to garner a 'different' or more expanded response from the patient was also motivated by an aim to verify patients' awareness of their being affected by bvFTD.

The patients who resisted the presumption of illness or concern were found to only claim but not demonstrate their understanding that they are healthy or unconcerned; that is, these patients were unable to articulate an expanded response in which they would account for their denial of being ill. Thus, the degree to which they understood that aspect of their life situation related to bvFTD remained uncertain. For the other two patients, however, their more elaborated responses were found to better demonstrate their degree of understanding and access to personal experience. The patient who affirmed his illness drew from a range of interactional practices to upgrade his epistemic authority, whereas the patient who displayed uncertainty drew from interactional practices that more clearly revealed his lack of knowledge.

By examining the fine details of interaction between bvFTD patients and a doctor, we were able to show that 'degree of awareness' is not identical for all patients. Our investigation has focused mainly on how patients display knowledge and awareness concerning one important domain of their lives: their specific knowledge of the negative effects of their illness, their concerns about their illness and their perceived concerns of family members. But it also seemed that patients'

displayed lack of awareness had implications that reached much further and deeper than the patients' illness per se. It also dealt more generally with the patients' degree of mastery over his or her first-hand experience, how well patients understand others' perspectives and how they seem generally unconcerned or unaware that their responses may generate negative inferences from others (i.e., they lack awareness of essential information such as their state of health and thus are not competent in managing their own lives). Thus, our analyses of single sequences of interaction seemed to go a long way in revealing the extent to which persons may display (or fail to display) themselves as competent social actors.

## Notes

[1] 2 patients from this group had a mixed clinical profile. One also had a motor neuron disease known as amyotrophic lateral sclerosis (ALS) and another had progressive supranuclear palsy (PSP).

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## Appendix

Transcription Notation (adapted from Jefferson 2004)

| Symbol | Meaning |
|---|---|
| [ | Starting point of overlapping speech |
| ] | Endpoint of overlapping speech |
| (1.5) | Silence measured in seconds |
| (.) | Silences less than 0.2s |
| wo:rd | Prolongation of sound |
| (word) | Transcriber's guess |
| wo- | Speech cut off in the middle of the word |
| <word> | Spoken slowly |
| >word< | Spoken quickly |
| °word° | Spoken quietly |
| WORD | Spoken loudly |
| word | Emphasis |
| word=word | Latching (no audible break between words) |
| .hhh | Audible inhalation |
| hhh | Audible exhalation |

| | |
|---|---|
| wo(h)rd | Laugh particle (or outbreath) inserted within a word |
| heh/huh | Laugh particles |
| ↓word | Marked falling intonation (not phrase final) |
| ↑word | Marked rising intonation (not phrase final) |
| . | Falling intonation at end of utterance |
| ? | Rising intonation at end of utterance |
| , | Continuing intonation at end of utterance |
| ↺word | Fall-rising intonation |
| ↻word | Rise-falling intonation |
| ((sniffs)) | Audible non-speech sounds |
| *italics* | Non-verbal behaviour (actor indicated by initial) |
| → | Analyst's signal for actions under discussion |

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