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Social Interaction

Video-Based Studies of Human Sociality

Companions' Interventions on Behalf of Patients: Differences According to the Patient's Capacities

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Abstract

Some patients require a companion to help them answer questions from medical personnel. How the companions do so may depend, in part, on the nature of the patient's condition. In the case of the patient with a learning disability, we find the companion tending strongly to respect the patient's agency and entitlement to speak to their own experiences, by a) allowing the patient time to volunteer the answer to the question themselves, b) glossing inadequate answers as being a temporary failure to remember and c) constructing a no-problem answer (extending previous findings by Antaki and Chinn, 2019). In contrast, with a patient who is examined for or has a diagnosis of epilepsy or multiple sclerosis, we see the companion tending to take a more proactive and interventionist approach. We discuss our findings in the light of differences between the powers and capacities attributable to people with learning disability, epilepsy, and multiple sclerosis, and the different entitlements that their companions may assume in speaking for them.

Keywords: companions, health care encounters, patient's agency, conversation analysis

1. Introduction

Some patients will on occasion need to rely on a companion to help them communicate with a medical practitioner. The companion can (but may not) mediate or “broker” (as it is termed by, for example, C. Raymond, 2014,a,b; Chinn, 2022) between the two parties. What right does a companion have to articulate the thoughts of the patient that they are accompanying, or to answer in their place? Does the *kind* of atypical capacity make a difference in terms of companions’ orientations to their entitlement to speak for the patient?

A number of studies have shown interlocutors guiding and supporting people with aphasia, (reviewed in Volkmer et al. 2022), with current recommendations to companions to prefer that kind of respectful help at the expense of jumping in inappropriately. But some patients are broadly cognitively challenged – by learning disability (see Antaki et al., 2020), dementia (Webb, 2017), amnesia (Hamann and Nielsen, 2021) and so on, and may not be able to access their own life-histories to answer questions appropriately. Indeed, some people who may be living with conditions which, although they are not necessarily associated with cognitive deficit, entail such emotional distress or negative affect that they might experience serious communicative difficulties (as Pino and Land report in their analysis of consultations in palliative care, 2022). For such patients, it is not (just) the words as such, but the capacity to draw on their experiences appropriately when asked.

Of course, there can be all sort of reasons which prompt or require the companion to intervene - the health worker can ask them directly, the patient may be otherwise engaged, and so on, none of which imply that the companion has done anything interactionally untoward; as Pino and Land observe, “companions’ interventions on behalf of patients should not be treated as autonomy-detracting before establishing whether other participants’ actions or other local contingencies prompted (and warranted) those interventions” (Pino and Land, 2022 p. 397). That is an important condition, if we are interested in the kind of intervention which erodes the patient’s agency and authority. Here, we are after situations in which the patient could answer, or could answer adequately, but the companion plays a trump card.

One way to understand the companions’ dilemma in these more free-range situations, following Antaki and Chinn (2019), is to see it as a matter of choosing where to place their mediation on a spectrum of inoffensive to overbearing intervention. At one end, the companion designs their turn to respect, as much as possible, the fact that it is the patient who “owns” the right to know about their life; at the other end, such respect is abandoned for reasons of, for example, the urgency or importance of the correct response. In their data, one sees deference to the patient when it’s a matter of, for example, the patient’s preferences for football teams, but intervention when there is potential confusion over appointment arrangements.

Antaki and Chinn found that interventions tended to be delicately delivered. Their data came from primary care consultations where the patient had a learning disability. The question arises of what might happen to others who might also have communication problems, but a different kind of disability. It may be that other conditions may imply different kinds of capacities which would allow or require the companions to be less delicate, and more blunt and assertive. Or indeed, as Pinot and Land (2022) found in their study of consultations in palliative care, the reverse – where the companions went out of their way to promote and enhance the patient’s right to answer.

What is new here, then, is to ask whether the *nature* of the person’s incapacity makes a difference regarding their companion’s displayed degree of entitlement to speak on behalf of the patient. The comparison we shall make is between people with a learning disability on the one hand, and, on the other hand those with multiple sclerosis or epilepsy. Cognitive disorders are common in people with epilepsy (Novak et al., 2022), as with people suffering from MS-disease (Bagert, Camplair & Bourdette, 2002). These dysfunctions include memory, attention and information processing related deficits (*ibid*s). It’s important to note that we don’t assume that a patient with multiple sclerosis or epilepsy must have memory gaps or other cognitive reasons not to have the capacity to answer questions – just as we don’t assume that a person with a learning disability must necessarily not have capacity – we take it only that *their condition can be understood by companions as allowing for that possibility*. On that basis, then, we shall see whether companions of these latter patients intervene differently from those accompanying patients with a learning disability, and, in the conclusion to the paper, we shall speculate on why this might be so.

2. Overview

We examine recordings of consultations in three different health care settings. In all cases, we identify examples of the companions ‘interventions when the patient does not answer, or answers in a way that is treated as somehow inadequate. In one set of cases, the patient has a learning disability, and in the others, the patient has or is being diagnosed for epilepsy or multiple sclerosis. These specific neurological problems offer an interesting research context, as research on companions’ role there is scarce. There are articles on companions role in differentiating between epilepsy and non-epileptic seizure disorders (Robson, Drew & Reuber, 2016) and on comparing companion involvement in telephone and face-to-face clinical consultations (Ford & Reuber, 2023), and some empirical video-based work on seizure clinics (Doehring, 2018), while literature on companions’ role in multiple sclerosis encounters is still scarce (see however Kesselring et al. 2022 on perceptions on involvement of families and caregivers in consultations).

Both epilepsy and multiple sclerosis have multiple consequences (see Chiaravalloti & DeLuca, 2008; Novak, Vizjak & Rakusa, 2022) which might restrict patients' ability to participate in communication in the encounter (Yorkston, Baylor & Amtmann, 2014). What's relevant here, crucially, is that both kinds of patients can be understood by their companions to lack access to certain experiences or memories, simply as part of their condition or present symptoms to be diagnosed. The patient with learning disabilities will have access to memories and experiences but may have difficulties putting them into words; patients with the other two conditions might have blanks where those memories would have been. The question to ask is whether companions orient to this difference when they choose to intervene on behalf of the patient.

3. Data

The data from interactions where the patient has a learning disability was collected by the third author from general practitioner practices in a major UK city.¹ Practices were eligible if they were taking part in a national scheme to complete annual health checks with patients registered as having intellectual disabilities (Slowie & Martin, 2014). An initial invitation to take part in the study was made by practice staff to patients with intellectual disabilities who were over 18 and did not need support from an interpreter. A researcher followed up with a home visit to complete consent procedures, including recruiting research 'consultees' for patients deemed unable to give informed consent regarding their participation. Ethical approval was given by an NHS Research Ethics Committee (Ref:16/LO/0455). Altogether 33 health checks were video-recorded, conducted by 14 practitioners from 10 GP practices. Four (29%) of the practitioners were practice nurses, the others were doctors and one physician associate. Most patients (n=29, 82%) attended accompanied by a family member (n=9) and/or at least one paid carer or supporter (n=23); of these, 4 had a non-speaking patient, leaving 25 that are useable for the purposes of the analysis.

For the data on interactions involving patients with epilepsy and multiple sclerosis, data was collected in a research project 'Reliable knowledge for health care: Process and practice of shared decision making' led by the first author and funded by the Social Research Council within the Research Council of Finland (Dec.Nr. 358418). The corpus represented recordings of 58 neurological consultations with 8 neurologists, 4 nurses, and 25 adult patients. In 14 cases there was a companion present. One case where the companion was contacted by phone was left out of the collection. The 13 cases were both first and follow up visits with 9 patients, some of them with multiple visits. These consultations were more thoroughly analysed, resulting in 75 sequences where the companion intervened on behalf of the patient. Patients were invited to participate via the

¹ This paragraph (on the arrangements for data collection with patients with LD) is an edited version of the same material in Antaki & Chinn (2019).

neurology clinics involved in two major cities in Finland. Some of these encounters were for diagnosing the patient due to seizures or other neurological problems that may or may not end up with diagnosis, some for checking the suitability of prescribed medication to already diagnosed epilepsy or multiple sclerosis patients. The companions were all family members, spouses living with the patient, or parents or siblings. It is noteworthy that in cases of possible epilepsy diagnosis, the neurologists routinely contact the patient's family member or close friend at some point of treatment process. This is because during seizures, the patient is unconscious, and thus naturally not able to have knowledge on the event. Ethical approval was received from Pirkanmaa Health District ethical board (nr. 7/2021, date of minutes Oct 19th, 2021).

4. Analysis

In the following sections, we will use examples from the three medical settings described above to see how the patient's apparent inability to report trouble is handled by their companions. We shall see examples of interventions by the companion where the patient has been asked a question, but alternatively, either offers no answer after being given an appropriate opportunity, offers a response which is treated as ill-fitted to or inadequate for the question or is given no time to offer an answer before the companion self-selects to answer. These opportunities to intervene are common to both corpora; what we shall see is differences in how the companions take them.

In the case of patients with a learning disability, we find the companion tending strongly to respect the patient's agency and entitlement to speak to their own experiences, while with patients being diagnosed or having a diagnosis of epilepsy or multiple sclerosis, we see the companion tending to take a more proactive and interventionist approach.

4.1. Patients with a learning disability

We begin with cases from a series of primary health care interactions for people with some kind of learning disability (Antaki & Chinn, 2019). The questions asked in these health checks ranged from lifestyle issues (whether the person had a job, was in a relationship and so on) through to healthy lifestyle issues (for example, how they toileted) and potential medical symptoms. Most patients, but not all, came with a companion to help them cope with the questions.

Antaki and Chinn argue that the companions ranged their interventions along the gradient of sensitivity and entitlement, with most of their interventions clustering towards the more sensitive formats, claiming less entitlement to speak on the patient's behalf. We may borrow a case they report to stand as example

1 (below).² Here an older man with a learning disability ("Cliff") has been asked by the nurse about his balance in walking. The man is accompanied by a paid carer, "Louis".

Example 1. Shopping [companion is a paid carer]

LD HC7 15.06

563 Cliff: When you carry your shopping, .hh have i- your lef-
564 your left arm your left arm, .h so it balances
565 as you wal- as you're go- grabbing on (.) t' the rai:ls.
566 (.)And that's what I've been been doing.
567 Nurse: Okay [perfect
568 Cliff: [So far >t'ch wood< ((taps table)) 's bin going good.
569 Nurse: And .h
570 Louis: Wu- one thing with the stairs that you told me this morning
571 Cliff is that (0.7) you find it hard sometimes with those
572 stairs at your house don't you=and that's why you wanted
573 the oh tee.
574 Cliff: My stairs?
575 Louis: Yeah

This example is helpfully clear in the way that the companion intervenes to account, sensitively, for an important absence in the patient's answer.

Cliff's answer at line 563-568 is positive and receipted as such (at line 567) by the nurse. As the nurse prepares to proceed to the next question (line 569), the companion intervenes to take a turn, marked by the cut-off preface "wu-" (probably "well"). The "well" signals a disjunction, or interruption of the progress of the interaction on the current basis ("relative to the expectations for action established in the prior turn or sequence", as Heritage 2015 p 88 puts it); so, something contrary is coming up. But note how it is introduced - by a cataphoric phrase ("one thing with the stairs ..."). This forefronts the *stairs* as the topic, not, as becomes plain, Cliff's trouble with them. Moreover, Louis is careful to defer to Cliff as having epistemic priority: "... that you told me this morning", and to assert Cliff's mastery of the problem ("... that's why you wanted the oh tee [i.e. the occupational therapist]"). Louis has managed what would otherwise sound like a contradiction or correction (after all, Cliff had asserted that "it's bin going good", line 568) in a way that respects his greater entitlements.

Sensitive delivery

We may set out examples of these kinds of sensitive delivery: a) allowing the patient time to volunteer the answer to the question themselves, b) glossing the

² This is the only case we borrow from Antaki & Chinn's 2019 article; in the rest of what we report here, we went back to Chinn's corpus of primary care consultations to find fresh cases, so as not to duplicate the examples.

problem as being a temporary failure to remember and c) elaborating a no-problem answer.

a) *allowing the patient time to volunteer the answer to the question themselves*

In example 2, below, we again, see the companion intervening sensitively to correct a misleading implication of the companion's response. In this case, a nurse is asking a patient with learning disability a series of questions about her lifestyle, including to what degree she is physically active.

Example 2.

LD HC04 08.30 play tennis [companion is patient's mother]
01 Dr: anything else you enjoy, in terms of sport.
02 (1.0)
03 Pat: (like) () tennis,
04 (0.8)
05 Comp: tennis but you don't actually play tennis, Jeanie, you
06 like [tennis but you don't actually play tennis
07 Dr [you like tennis

The patient's answer at line 3 is not completely hearable, but seems to be interpreted by the companion as not well-fitted to what the pragmatic force of the doctor's question would have projected. But once again, the companion designs her intervention to avoid unmitigated and immediate correction. She allows a gap to appear at line 4, in which the patient may have further elaborated and revealed whether or not she herself played tennis. When that does not come about, the companion intervenes by first displaying her understanding of the patient's response (with an echo of the theme word "tennis"). Only after such recipient design and deference, does she clarify that a mistake has been made, offering a candidate response to the patient – that she likes tennis, but that she does not play it. This is very different from a bald correction of the form "no, you don't play tennis".

Allowing the patient time to themselves volunteer the answer to the question makes clear to all parties concerned that the companion is willing to withhold what they know. They sacrifice the smooth onward pace of the question and answer exchange (what Stivers and Robinson 2006 call the 'preference for progressivity' that is generally respected in conversation) in favour of an overt deference to the patient's rights to answer for themselves – even if it takes valuable interactional time.

b) glossing the problem as being a temporary failure to remember

If the companion gives time for the patient to answer, as above, they face a difficulty if the answer is not forthcoming. They could intervene, but they need to choose how – call attention to the patient’s general cognitive deficit, or cast it as something less atypical. Example 3, below, shows, as in example 1, the companion can design their intervention as matter of the patient’s memory, rather than a failure to know what the answer is. The companion thus encourages the patient to produce the answer themselves instead of intervening by answering the question.

Example 3.

LD HC10 01.15 days in hospital [companion is a paid carer]

01 Nurse: yes, an' didn't you have a couple of days in hospital?
02 (3.0) [in which Patient has "thinking face"]
03 Comp: nudges P gently)) remember when y'were in hospital
04 (2.0)
05 Pat: that was before, I'm not sure ()
06 Nurse: okay, but you've been alright

In example 4 below, again both the doctor and the companion (in this case the manager of the patient’s residential home) leave time for the patient to respond. At line 5, there seems to be some show of uncertainty the manager leaves a five second gap, and then comes in on the patient’s behalf.

Example 4.

LD HC18 c. 15.00 angry or upset [companion is a manager of patient’s residence]

01 Dr: and what about here at the residential home.
02 (0.8)
03 Dr: does anything here get you (.5) angry, (.5) or upset
04 (1.0)
05 Res: no I () () .hh ooh, .hhh
06 (5.0)
07 Man: .hh you've mentioned about [noise]:=

Once again, note the delicacy of the companion’s intervention: she doesn’t make any claims about the patient’s state of mind, but makes an observation about the noise that the patient had (merely) “mentioned”; a sort of repair initiation, playing that the patient could indeed have come up with it themselves. There are a number of ways one could conceptualise this kind of disguise, traceable back perhaps to the notion of avoiding negative face, as introduced into pragmatics by Levinson (1983, and more fully in Brown and Levinson (1987). When leaving the patient time to come forward themselves doesn’t work, attributing the failure to a temporary memory lapse protects against calling

attention to the medical facts of the matter: that the patient is living with a more permanently atypical condition.

c) *elaborating a no-problem answer*

A feature of interactions which involve going through an agenda of items which may reveal unwelcome news is for the questioner to be 'optimistic' – either by designing their questions to imply a positive response, e.g. "you don't smoke, do you?" or to put a positive gloss on the answer the patient gives (perhaps "well that's less than you used to" (see, for example, Peräkylä's review of such optimism by psychotherapists, Peräkylä, 2012). Usually this would fall to the practitioner; but it is also a device available to the companion. Consider the example below. It starts by the nurse's optimistic question "an' you've got not problems", to which the patient gives a quiet "no". The nurse repeats the question at line 4, this time nominating the companion to answer. The patient nevertheless does answer (line 6) but in overlap with the companion, who embarks on an elaborate account of her justification in giving a positive, no-problem report.

Example 5.

HC17 08.10 got no problems [The companion "Amelia" is a relative of "Karen" the patient]

01 Nurse: an' you've got no problems
02 (1.0)
03 Pat: °no° [n
04 Nurse: [an' Amelia's got none to report:
05 Comp: mm-mm [(no (when you))
06 Pat: [no I haven't
07 (1.0)
08 Nurse: °no° I think if Karen had, you'd [to Comp] say something
09 Pat: [mm
10 Comp: [oh yes she would say something [she'd (be telling me
11 Nurse: [yeah, yeah (.5)
12 Nurse: she always comes in all ((mimes 'carefree')) (.1.5)
13 [jolly happy
14 Comp: [(laughing)
15 Nurse: I think if she came in a bit- (1.0) [()
16 Comp: [yeah (quite
17 low / I know) ['cos [straight away she goes at the weekend=

18 Nurse: [down
19 Comp: she comes back, [goes on to explain why Pat is in a good mood]

What we see in this extract is not only the nurse, but also the companion, designing the talk in a way to excuse the patient from reflecting on her own state of mind - or to bypass the need for her to do so. Even though the patient has given what seems to be a satisfactory answer in line 3, at line 4, the nurse nominates the companion ("Amelia") as accountable for reporting on the

patient's problems. The invitation to the companion is designed in the "optimistic" manner projecting a positive response. The companion, in line 8, elaborates the positive picture with her own, external, evidence that the patient is feeling well, with two sources of evidence – the counterfactual, that if the patient was not happy, she would tell the companion; and secondly, with an anecdote about the patient returning from a weekend, showing evidence of being in a good mood. Note that the companion is careful to moderate her answer, as we have seen above, by referring to the patient and invoking the patient's primary experience.

We have seen, then, illustration of three ways in which a companion may design their part of a conversation, both to attend to the need to provide medical information but to do it in such a way that respects the patient's rights. So even when intervening on behalf of the patient, the companions treated the patient as the principal respondent and reinforced the patient's agency by encouraging them to produce an adequate answer. Now that we have established the kind of sensitivity that may be shown to the patients with a learning disability, we can turn to the case of patients who live with different kinds of condition. Do their companions exhibit the same degree of sensitivity?

5. Patients with Epilepsy or Multiple Sclerosis

5.1 From sensitive to entitled delivery

Similar to encounters with people with learning disabilities, the questions asked of patients consulting a professional for symptoms or medication for epilepsy or multiple sclerosis ranged from lifestyle related questions to medical symptoms. As with LD, in these cases, companions' responses altered between more and less sensitive in terms of attending to the epistemic rights of patients to their own experience. However, unlike with learning disability patients, entitled responses by the companions were more prominent.

In this data, it was not uncommon that when answering on behalf of the patient, the companions showed entitlement to know as much or even more of the patients' living conditions, symptoms or ongoing care procedures than the patients themselves.

In the more sensitive end of the gradient, the companions would take the turn only after being involved by the patient or professional (neurologist or neurological nurse) (Examples 6 and 7). Towards the more entitled end of the gradient, the companions would take the turn after the patient had given an inadequate response (Examples 8 and 9), and in these cases deliver the seemingly missing information without attending to the patient's rights to their experiential knowledge. At the most entitled end of the gradient, the companions would self-select straight after the professional's question (Examples 10, 11 and 12), here again, showing no or minor concern to patient's rights as the 'first

owner' of their experiential knowledge. In all examples, shifts of gaze directions and gestures are marked when analytically relevant. Gloss lines in addition to idiomatic translation are added when the word order differs from the English version, also when analytically relevant.

d) Intervening on involvement by the patient or professional with orientation to the patient's rights

In examples 6 and 7, the patient has arrived at the consultation to discuss new medication for her multiple sclerosis. She is accompanied by her sister who is involved in the discussion by the doctor (line 02), following the patient's self-critical account of not remembering her own address (line 01). This is a follow up visit, MS having been diagnosed earlier.

Example 6. (MS 28)

01 P: [Mä en muistanu osoteffta~~f~~
[I couldn't remember the address~~f~~
[((P turning halfway towards her sister))

02 D: [No (.) muistasko sisko.
[well (.) would the sister remember.
((D gaze at P, glancing at C))

03 C: Eiks se ollu Kotipolku.
Wasn't it (Name of Address) .

04 P: Kyllä mää sen verran muisftinf.
I did remember that fmuchf.

05 C: Mut oota mä olin kakskytkaks bee (.)kaks (.) ni sul oli kakskytkolme
But wait mine is twenty-two bee (.) two (.) so yours is twenty-three

06 D: No ni.
Right.

07 C: Bee. [fmä muistan sii-~~f~~]
Bee. [fI remember bec-~~f~~]

08 D: [Kakskytkolme] bee.
[Twenty-three] bee.

09 ()

10 D: Ei sitä kukaan tarkista [tässä] [vaan] testataan osaaksää kirjottaa.
Nobody will check it [here][just] testing whether you can write.

11 ?: [Mm.]

12 ?: [Joo.]
[Yes.]

13 ((giggling))

At the beginning of the consultation the doctor has asked the patient to write down answers to some specific questions. The patient is standing up, filling the form at the desk, the companion sitting behind her. At the beginning of the sequence, she stops filling up the form, turns halfway towards her sister, and takes the turn at line 01.

At line 03, the companion takes the turn on request by the doctor as the patient has made clear that she could not fill in the form as expected. The patient's smiling at the end of her utterance (line 01) implies a certain embarrassment of not remembering her own address. The companion's response is designed as a request for confirmation that is directed to the patient ("Wasn't it Kotipolku"), and this way respects the patient's primary right to know her own address even if the patient has revealed that she does not remember it. The companion continues by making explicit that she is also doing remembering – and infers the street number of the patient with the help of her own address (line 05) (apparently, they live close to each other on the opposite sides of the same street). She also starts to explain how come she is able to memorize the address (line 07), and this way shows orientation to the patient's superior right to know about her personal matters.

Example 7. (MS 28)

01 D: [Nii tällästä] niinkun öö (.) fatiikkiin ja
[So this type of³] like erm (.) for fatigue and

02 tämmöseen neuropsykologisiin [oireisiin niin ei.
this kind of neuropsychological [symptoms so not.
[((P shakes head))

03 (0.2) ((C glancing at P; P turns to C))
#Fig 1

04 P: [E:i.] ((gazing at C))
[No:.]

05 C: [E:i.] ((gazing at P))
[No:.]

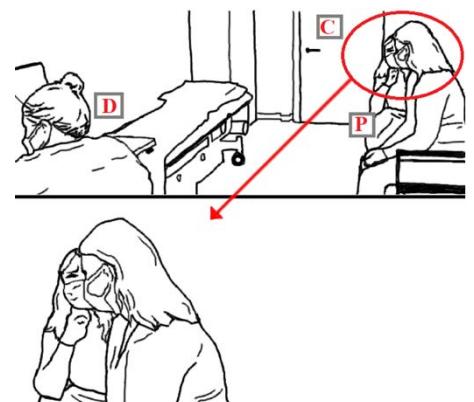
06 (0.5) ((C smirks; C and P turn to gaze at D))

07 D: Ei o.
There is not.

08 C: Joo ei oo mitään.
Yes there's nothing.

09 (1.0) ((P and C gazing at each other, C frowning, eyebrows raised
head move down))

10 D: Okei?
Okay?



³ The doctor is referring to rehabilitation

11 (4.0) ((P and C gazing at each other, C frowning, raising eyebrows))

12 C: Ku ei muuta oo ollu ku nää [(1.0) fyssarit.
As there's been nothing but these [(1.0) **physiotherapists**.
 ((C gesturing and gazing at P))

13 P: Nii.
Yes/Right.

14 C: Fi- fyssariasiat ja (1.0) ja mistään ei oo kyllä
Phe- physiotherapist issues and (1.0) nowhere has there

15 tomosta (2.0) tietoa tullu sitte.
that kind of (2.0) information been available.

16 D: Ahaa.
 Oh.

At line 01, the doctor is asking whether the patient has previously participated in a rehabilitation that is reported in the patient record. (Later it turns out that the question is about a mistake in the record, and the rehabilitation has in fact not taken place). The patient does not recognize having taken part in this. The doctor specifies her question (line 1) clarifying what kind of rehabilitation is noted in the record and asking for a confirmation that the rehabilitation has not taken place. The patient allocates the turn to her companion by turning towards her (line 03), as if asking her companion to give the information she is not quite able to give herself.

The companion glances at the patient while the patient starts shaking her head turning to her sister (line 03). In achieving gaze-contact (lines 04 and 05) they both state “No” in overlap with each other. The doctor, however, does not treat the response as sufficient (line 06), but requests for confirmation, which the companion gives (line 08). It is noteworthy that although here, the companion treats herself entitled to answer instead of the patient, she is responding while remaining in gaze-contact with the patient, displaying with her gaze, frowning and raised eyebrows (lines 09 and 11) that she is not sure about the answer and expects the patient to confirm her response (Stivers & Rossano, 2010; Heller, Schönfelder & Robbins, 2023). The lengthy silences at lines 09 and 11 also show how the patient herself is given space to deliver an answer to the doctor’s question.

Here, the companion and the patient align as a team (Lerner, 1993; Kangasharju, 1996), showing to the third party with their mutual gaze that they are searching for the correct answer together. The patient is given space to answer but as she does not, the companion takes the turn yet showing by her gaze and facial expression that she treats the patient as also having the entitlement to produce the correct answer.

These cases have similar features as the ones with learning disability patients, where the companion gives space for the patient to answer themselves before

intervening. The companions show concern to the patient's rights by waiting for either verbal or visual turn allocation by the patient or the professional, and by confirming their understanding from the patient either verbally or through mutual gaze and facial expression (such as eyebrow lifts). However, unlike in many of the learning disability cases (see examples 1, 3, and 4), the companions here do not make an effort to encourage the patient to produce the answer themselves.

e) *Adding to or accounting for the patient's description*

As with learning disabilities patients, companions of multiple sclerosis and epilepsy patients could intervene to add something to the patient's answer or account for an important absence in it (see Examples 1 and 2). However, unlike with learning disability patients, the companions showed less concern to preserve the patient's epistemic authority but instead, displayed considerable entitlement to know about the patient's problem, as in Example 8 below:

Example 8. (Epi 8)

01 N: [Ja tuota (.) sen jälkeen ei kuitenkaan mitään niinku tämmösiä
[and like (.) after that there hasn't anyhow been any seizure-
[((N gazing at P, P at N))

02 kohtausmaisia oireita oo ollu ennen ku nytte (.)
related **symptoms of this type before now** (.)

03 men- menneenä syksynä.
las- **last autumn.**

04 P: Nii. oikeestaan näin voi sanoa että ei oo ollu
PRT
Actually one could say that there hasn't been

05 [.hhh (.) niinku (2.0) [mitään?
[.hhh (.) like (2.0) [anything?
[((P gaze to side)) [((C gaze at P))

06 Mut tokihan mä oon sen jälkeen niinku [sairastunu
But I have after that like [got ill
[((P gaze at N))

07 sit masennukseen,
with depression then,

08 N: Joo?
Yes?

09 P: Ja (1.0) kaikkii muita vaivoja on kyllä ollu.
And (1.0) all other problems I have indeed had.

10 C:→Ja [mui[sti]häiriö [on (-)]
and memory deficit is
And[me[mory] deficit [is (-)]
[((P gaze at C, N gaze at C))

11 N: [joo.]
[Yes.]

12 P: [ja muisti häiriöt [että
[And memory] deficits[so
 $[(N \text{ gaze at } P))$ $[(P \text{ gaze at } N))$

nää (.) muisti on kyllä heikentynä aika (.) [paljonkin.]
these (.) my memory has indeed weakened quite (.) [a lot.]

The patient and her companion have arrived for their first visit at the neurology clinic where they are first interviewed by a nurse. They are sitting side-by-side, gazing at the nurse who is sitting on the other side of the table. They have gone through the patient's previous seizure related symptoms.

The nurse asks a question on past seizure-like symptoms addressing the patient by her gaze (lines 1-3). The patient shows signs of hesitation in her answer with her turn design “Actually one could say” (line 4), gazing to her side as if recollecting her thoughts (lines 5-6) and pausing mid-turn (line 5). At line 5, during these hesitations, the companion turns towards the patient. She mentions her depression and finishes her turn with a reference to “all other problems” (line 9). At this point the companion takes the turn to add one possibly significant problem: memory deficit (line 10). His turn is a plain assertion, stating the memory problem as a fact, as a continuation of the patient's turn. Only here do the other participants turn their gaze at the companion. The patient confirms her companion's addition, repeating his completion and slightly modulating it into plural form “memory deficits”, this way showing her epistemic ownership of the problem (Schegloff, 1996; Stivers, 2005). It seems that the patient's hesitant way of answering, with the generalized expression “all other problems” may have allowed the companion to interpret that his input is relevant at this point. However, unlike with patients with learning disabilities, there are no signs of working towards getting the patient to produce the missing knowledge herself.

A similar situation occurs in Example 9:

Example 9. (Epi 4)

01 D: [Liittyks siihen päivään jotaki erityistä (.)
[Was there something special in that day (of the seizure)
 $[(D \text{ gaze at and position towards } P, C \text{ gaze at } P, P \text{ gaze at } D))$

02 niinku (.) mitään poikkeavaa,
like (.) anything exceptional,

03 olitsä jotenki (.) syöny ja juonu
 had-S2+Q somehow eaten and drunk
Had you like (.) eaten and drunk

04 normaa[listi, (.) [(--)]
 normally
normal[ly, (.) [(..)]
 [((D head forward towards P))]

05 P: [nnn [Olin] just käyny
 [nnn **[I had] just**

06 hakemassa lävistyksen [((nauraa))]
gotten a piercing [((laughing))]

07 C:→ [Neulakammo.]
[Needle phobia.]
 [((C gaze at D, pointing gesture at P))]

08 P: **£N[iif.**]
£Y[esf.]

09 D: [Mitä?] [What?]
 [((D turns gaze at C, abruptly forwarding his head towards C))]

10 C: Hän on ↑neulakammonen ni,
She is ↑needle phobic so,

11 D: Okei?
Okay?

12 P: Niin [ni] olin just käyny hakemassa lävistyksen £ennen sitä£.
Yes [so] I had just gotten a piercing £before that£.

13 D: [Joo?] [Yes?]

14 D: Okei? Joo?
Okay? Yes?

The patient and her companion have arrived at the neurology clinic for the first time. They have had an interview with a nurse and now they are seeing a doctor. The doctor has asked the patient whether there had been anything exceptional during the day when she had had a past seizure before the more recent one, for which they are attending the clinic. This earlier seizure was one where the companion had not been present. The doctor then inquires whether the patient had noticed anything exceptional on the day of the seizure. The patient and the companion are sitting beside each other, the doctor behind the desk. The doctor is gazing at the patient the whole time of the sequence preceding the companion's intervention at line 7, the patient's gaze is at the doctor, and the companion's gaze is at the patient.

The doctor's question is directed to the patient verbally, with the singular "you" (line 3), by gaze, and gesturally by moving his head towards the patient at the closure of the question (line 4). The patient tells that she had had the seizure after having just gotten a piercing. At the transition relevance place of the patient's answer, in overlap with her laugh, the companion adds to it an

explanation of the possible connection between the event of getting a tattoo and the past seizure (line 7): turning his gaze from the patient to the doctor and pointing briefly at the patient, he says “Needle phobia”. In overlap with the patient’s confirmation of this, the doctor makes a repair initiation “Mitä” (what). Such open class repair initiators are a common way to initiate repair in Finnish conversation, there existing more formal ways, such as “Anteeksi” (sorry) (Haakana, 2011). Open class repair initiators are often used to deal with problems caused by overlapping talk, or as reacting to unexpected turns in interaction (ibid 2011). The doctor’s abrupt head turn towards the companion indicates that here the latter use may be the case: treating the companion’s intervention as unexpected. The patient confirms the notion made by the companion (lines 8 and 12) thus displaying her primary right to know about her personal phobia. Here, the companion’s addition again takes a rather proactive approach, not showing signs of delicate delivery as in learning disability consultations.

In both examples, the companions seem to promote the institutional task of the visit, that is they add potentially relevant information to what the patient has already stated, for well-grounded diagnostic and/or treatment decision. However, unlike in the cases of patients with learning disabilities, the companions tend not to attend to the patient’s agency and primary rights to speak about their own experience as strongly.

f) Self-selecting after the doctor’s question

There were occasions in both epilepsy and MS consultations where the companions oriented to themselves as having equal rights with the patient to discuss the patient’s situation. This was evident in cases where the companion self-selected after the doctor’s question before or in overlap with the patient. (Note: we leave out of consideration questions about anything to do with the time when the patient was actually unconscious, or partially conscious, in the duration of the seizure itself, which of course the patient cannot answer from firsthand knowledge.)

Example 10. (Epi 8)

01 D: [But mitää tämäsiä läheisten (.) kuolle [lemia
 but any this-kind-of close-ones' deaths
[But any this kind of like (.) **deaths of close ones (.)**
 [((D gaze at P)) [((P gaze down, C to side))

02 esimer[kiks [taikka
for ex[ample [or
 [((D glance at C)) [((D gaze at P))

03 C: **Mm**,

04 D: Työ- työ- (.) työnkuvan [muuto[ksia,= work work work-picture changes
Work- work- (.) work-related [cha[nge,=
[(D glance at C))
[(D gaze at P))

05 D: =mitään tämmösiä on[ko], anything this-kind are+Q
=anything like this are [there],

06 C:→ [No] [ei oo muuta kun (.) Well not is anything but
[Well] [there's nothing else but (.)
[(D gaze at C))

07 heh [koira mikä häneltä kuoli. dog that her+of died
heh [the dog that she had died.
[((C taps P on arm, gaze at P; P turns gaze at C))

08 D: [Nii. Kyllä.
[Right. Okay.
[((D gaze at P))

09 C: [(--)]

10 P: [(--)] koira kuoli ja (.) ja tokihan öö työnantaja (.) dog died and and really employer
[(--)] dog died and (.) and really eh the employer (.)

11 Vehmaan kaupunki,
the city of Vehmaa,

12 D: **Mm?**

13 P: niinku (.) luopu meistä, öää (.) Vehmaan kaupungin ruokahuollossa like (.) **gave us up, eh (.) from the city of Vehmaa meal catering**

14 ja [siir]ryttiin (keittiöfirman nimi) palvelukseen, and [we mo]ved to work at (name of Kitchen service),

15 D: [Mm?]

16 P: Mutta emmää usko että se [nyt ois] (1.0)
But I don't think that it [would have] (1.0)

17 D: [Mm.]

18 P: mua niin hirveesftif.
(troubled) me so terriblyf.

The patient and her companion are on their first visit with the neurologist. They are sitting side-by-side with the doctor sitting on the other side of the table. The doctor is taking the medical history, asking about past seizures of the patient: how many there have been, how the patient feels and what happens during the seizure etc. Just before the example starts, he has asked whether there has been any big changes in the patient's life preceding the seizures and the patient has

reported that they have got married with her companion. At this point the doctor asks:

In lines 1-5 the doctor specifies examples of the kind of changes he is asking about. He keeps his gaze mostly at the patient during his question. At lines 2 and 4 he glances at the companion, but swiftly returns his gaze at the patient when reaching the TRP's. The patient and the companion turn their gaze away from the doctor at line 1 when he mentions deaths of the close ones. Thus, his question is addressed to the patient by gaze. However, at line 6 the companion self-selects and answers the question on behalf of the patient. His answer starts slightly in overlap with the doctor's question and is delivered as a straightforward fact: "there is nothing else but heh the dog that she had died". His answer was preceded by the patient delivering only one (positive) change – which also led to the doctor making specifying follow up questions. This may have lowered the threshold for the companion to produce an occasion that may have potentially meant some kind of life change for the patient. However, in his assertion "there is nothing else" he does not show signs of orienting to the patient's primary rights to respond or to know about the preceding exceptional occurrences. With his following report on the patient's dog having died he does however show some orientation to these by gazing at the patient when delivering the information. The doctor, on the other hand, does orient to these rights by immediately turning to gaze at the patient when receiving the companion's answer. And the patient also positions herself as having the epistemic right to know about the occasion by repeating the companion's statement about her dog having died (line 10) (Schegloff, 1996).

Example 11. (Epi20)

01 N: [Sillohan se aloteltiin sitten se (.) lääkitys?
[That's when we started then the (.) medication?
[((N gaze at papers, towards computer desk, P & C gaze at N))

02 N: [Ensin pienemmällä anno[ksella]
[First with a smaller do[se]
[((N gaze at P))

03 P: [Joo.]
[Yes.]
[((P nodding))

04 N: [Ja] nyt se on viissataaaaamuin [ja]
[And] now it's five hundred in the mornings [and]
[((N gaze at papers))

05 C: [Joo.]
[Yes.]
[((C nodding))

05 P: [nyt] se on] viissataa.
[Now] it is] five hundred.

06 C: [Joo. Kyllä.]
 [Yes. Indeed.]

07 N: [Joo? Joo.]=
 [Yes? okay.]=

08 C: [Nii. Nii.]
 [Yes. Yes.]

09 N: =[Kauankos se nyt on (.) [menny viissataa (.)
 =[For how long has it now(.) [been five hundred (.)
 =[(N gaze at papers)) ((N gaze at C)) ((N gaze at P))

10 [suurin piirtein.
 [approximately.
 [(N turn to computer))

11 C:→ ei se oo ku viikon.
 not it has but week-for
 It hasn't more than a week.

12 (0.5) ((C turns to P))

13 P: [Viikon [verran.]
 week for
 [For a [week]]
 [(P glances at C))

14 C: [Vähän [tois-] nii.
 [A bit [mor-] yes.

15 N: [Okei.]
 [Okay.]
 [(P & C gaze at N, N gaze at papers, marking))

16 P: Nii. [Olisko] sillai.
 would+Q that way
 Yes. [Would] it be so.

17 N: [Joo.]
 [Yes.]

Example 11 presents a case of a 73-year-old patient with epilepsy who has arrived in a check-up of his present condition with his wife. This is their second visit. Before meeting a neurologist, they consult a nurse at the clinic. The nurse is checking the present dose of the patient's medication, referring to the time when the medication was started. The patient and the companion are sitting side-by-side, and the nurse is seated at her desk, with the computer in front of her, but able to turn towards them with her office chair.

At line 9 the nurse asks a question "For how long has it now been five hundred", gazing first at the companion, then at the patient at the slight pause when the turn is still not prosodically complete, but semantically understandable. At the last part of her turn, she turns to look at the computer (line 10). At this point (line 11), the companion self-selects to assert that the medication has not been

continuing more than a week. The nurse's question is not allocated to either participant directly either verbally or by gaze. However, as the question is about the patient's medication, one might assume that he would have the primary right to answer the question. The companion also orients to this right, though only after her response, by turning towards the patient, observably for confirmation, which she gets (line 13). Thereafter the patient and the companion continue to negotiate on the proper timing of the medication period gazing at each other.

Example 11, continued.

18 N: [noin yks [viikko (.) viissataa.]
[About one [week (.) five hundred.]
[((N writing, gaze at papers))
[((P & C gaze at N))

19 C:→ [Noin viikko (.) sanotaan näin.] [Eiks se aina
[Around a week (.) let's say so.] [Didn't it always
[((C gaze at P, P at C))

20 (.) alkanu torstaina elikkä nyt vähä [vajaa vi-
(.) start on Thursday so now a bit [less than a we-
[((P scratches head))

21 P: Perjantain mä aina alotin.
I always started on Friday.

22 C: Perjantaina. No ni [per]jantain on (.)
On Friday. Right then [on Friday it is (.)

23 P: [Nii.]
[yes.]

24 C:→ [Perjantain tulee (.) se viikko.
[On Friday it will be (.) one week.
[((P & C turn to gaze at N, N turns to papers))

25 P: Joo.
Yes.

26 N: [j-]
[((N gaze at C))

27 C: [Nyt] täl viikol (.) [per]jantaina.
[Now] this week (.) [on Friday.

28 N: [Joo.]
[Yes.]

The nurse makes a request for confirmation of the duration of the period of the dosage of the medication (line 18). Here, again, the companion self-selects to give the confirmation unprompted (line 19), after which she turns to the patient to check her own understanding.

Following the negotiation with the patient (lines 19-23), the companion treats herself as the principal respondent of the request of confirmation when they have reached a common understanding with the patient. When they both turn towards the nurse, it is the companion who delivers the result of their negotiation: “On Friday it will be (.) one week” (line 24). And the patient confirms this at line 25.

Example 12. (*Epi 20, the same couple as in 11*)

The participants have talked about the patient’s sleeping habits when the nurse starts to give advice to the patient on the importance of sleep. The nurse is gazing at the patient during the advice and also during her following question on the patient’s exercise habits (line 7).

01 N: [Että tota noin sitten tulee levättyä ja jos et sä yöllä nuku (.)
[So like then one gets some rest and if you don't sleep at night (.)
/ ((N gaze at P, P & C gaze at N))

02 Ni jossain kohtihan se (.) [sitä] lepoo tarvitaan tietysti.
So at some point indeed (.)[that] rest will be needed of course.

03 C: [Yii.]
[Yes.]

04 P: Joo-o.
Yes.

05 N: Mutta se että tota noin (.) jos lepo ni liikuntaksi
But the thing that like (.) if the rest so also excercise

06 on vaa hyväksi että (.)
is only for the good so (.)

07 Jaksatko muuten liikkua.
have+strength-S2+Q by-the-way to-move
Do you have the strength to do exercise.

08 Siis tuleeko sun liikkuttua.
like have-habit+Q you-S2 to-move
I mean do you tend to go and do some exercise.

09 C: Ei kun [sen jalas]
No as [in his leg]

10 P: [(Ei) (--)]
[(No) (--)]

11 N: [Ai niin toi]
[Oh indeed that]

12 C: → **sil on jalka niin kau[heen] kipee.**
His leg is so terr[ibly] sore.

13 P: [Joo.]
[Yes.]

14 N: Nii nii ettei sillai [että.]
Right so that not like [that.]

15 C: [Nyt se] on yhen kepin
[Now he's using one crutch
[(C turns to gaze at P's leg))

16 [kans mut kotona menee]
[but at home he walks }

17 P: [Nyt mä oon yhden kepin kans.]
[Now I'm with one crutch.]

18 C: [kahden ka- kepin kans [kyllä on] vaikeeta.
[with two crutches [it's indeed] difficult.
[(C turns gaze at N))

19 N: [Niin nii.]
[I see.]

20 N: Joo mut (.) kuin pitkii matkoi jaksat kävellä.
Right but (.) how long distances can you walk.

The nurse addresses the patient with her question (line 8), both verbally with second person singular, and by her gaze. Yet, immediately at TRP the companion takes the turn and answers for the patient informing that the patient's leg is terribly sore. The patient orients to his right as the principal respondent by starting a turn at line 10 but cutting it short when his wife continues her answer. Thereafter, the patient confirms his wife's informing (line 13), and part of the extension of it (line 17). This pattern where the companion treats herself as the principal respondent without being addressed either by the nurse or the patient recurs throughout this consultation.

The companions' ways of intervening on behalf of the patient differed from those of patients with learning disabilities in terms of the displayed concerns to patients' rights to know about their own experience. While companions' interventions with learning disability patients were mostly sensitive towards the patients' rights to know and tell about their experiences, encouraging them to speak for themselves, with epilepsy and MS patients the companions asserted greater entitlement to knowledge about the patient's situation. Similar to companions of patients with learning disabilities, the companions of epilepsy and MS patients could give the patients space to respond (as in example 7), but would show less effort to get the patients to respond for themselves (unlike in examples 1, 3 and 4).

In examples 8-12, the companions displayed their entitlement by taking the turn without a separate prompt by the patient or the professional, either following the patient's answer adding to it, or self-selecting themselves as respondents before the patient. In these cases, they designed their interventions as plain assertions of the patient's condition, thus initially treating themselves as equally knowledgeable of the patient's condition and life circumstances as the patients.

In these cases, they could ask for the patient's confirmation after their intervention (example 11), but this was not always the case (examples 10 and 12). In these cases, the patients acted to regain their right to know about their own experience.

6. Discussion

We examined what happened when a companion intervened to answer on behalf of a patient with some kind of impairment. We knew from previous work on a range of consultations involving companions (well covered by Pino and Land, 2022) that intervening is a sensitive matter (noted by many, and set out by Antaki and Chinn, 2019) as matter of how much the companion steps onto the patient's knowledge domain. The question in our minds in this study was whether different kinds of impairment (or, rather, what could be attributed to the patient on grounds of different kinds of impairment) had any apparent influence on how the sensitivity was displayed.

We found that when the patient had a learning disability, the companion tended to make a show of respecting the patient's status by designing their intervention respectfully (repeating the findings of Antaki and Chinn, 2019): giving the patient time, treating their inability as a matter of a temporary lapse, and glossing the problem as a minor or indeed positive one. In sum, making it possible in various ways for the patient to produce an adequate answer themselves.

On the other hand, we found that when the patient had a diagnosis of epilepsy or multiple sclerosis, the companions showed a more varied range of intervention. When they showed entitlement to the knowledge concerning the patient's situation, they could avoid resorting to the kind of sensitive turn designs we listed above. They used plain assertions adding to or accounting for something that the patient had just said or self-selected in occasions where the patient might have had a primary right to answer. They could also show entitlement to know as much or even more about the patient's situation than the patients themselves. Yet, when the companions showed entitlement to speak for the patient, they did show some orientation to the patient's primary role as the respondent by gazing at the patient while responding or by starting to negotiate with them on the correct answer following their own response. In general, companions' interventions seemed to support and promote rather than prevent the exact representation of the patient's experience that is relevant for finding diagnosis and proper treatment for the patient's ailment.

Of course, there are multiple differences between the sets of cases besides the difference in the patient's condition. The learning disability cases were from the UK, and the business of those consultations was to do an annual health check; the other set of cases came from Finland, where the consultation was to diagnose or find treatment to a specific condition. The companions may have had different kinds of relationships with the patient and with the medical

practitioner. All such factors are uncontrolled. That means that any conclusions we offer must be tentative. Furthermore, our samples are yet small and further studies with bigger data-sets are needed to present any definite conclusions.

Nevertheless, we might venture a suggestion: it might be that when the patient has the socially vulnerable status of having a learning disability, companions may choose to act more sensitively in how they speak on their behalf. This would be in tune with various social movements towards greater respect for those with learning disabilities, exemplified by the *Valuing People* programme Department of Health (England and Wales) 2009, specifically aimed at reducing exclusion of people with learning disabilities (see also Roberts et al., 2013). Companions' generally more sensitive and respectful interventions – giving time, treating lack of knowledge as a temporary memory problem and so on – would be consistent with deleting what has been called the more “toxic” (Rapley, 2019) aspects of the learning disability identity. Conversely, when the patient has epilepsy or multiple sclerosis, with its less all-encompassing identity, such cognitive lapses as failure to remember may be treated as quite uncontroversial – part of a straightforward medical issue, and therefore less (or even not at all) socially accountable. So, their companion may intervene on their behalf with some degree of entitlement, and less orientation towards the sensitivities of encroaching on another's domain of experience.

We propose that these latter cases perhaps represent cognitive impairments that can be seen as features of illness that has developed or has been diagnosed later in patients' life (as is the case in these data) and might thus have less influence on a person's assumed need for help in communicating. Learning disabilities on the other hand have been part of a person's life since birth, forming a more stable and long-term barrier to participation, which might call for more extensive attention to preserving the agency of the patient. This, in turn, may have an effect on the companions' orientations. In other words, it can be argued that what we have seen here is, in the microcosm of conversational exchange, the playing-out of the social meanings of disability, and the rights and entitlements of people with disabilities and those who support them.

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