

How to live with spoiled identity: stigma management in aphasic families

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In recent years, aphasiological research has shifted from cognitive to communicative and psychosocial aspects of aphasia. These dimensions of chronic illness are captured in the International Classification of Impairments, Disabilities and Handicaps (ICIDH-2), developed by the WHO.

In terms of the ICIDH-2, *participation* refers to the impact of illness on a person's involvement in life situations. In this paper, I will apply Goffman's concept of *stigma-management* to aphasia. It will be argued that this notion is useful for describing and analyzing processes of social desintegration, i.e. a reduction of the *participation*, as a consequence of faulty verbal behaviour in interaction.

According to Goffman, *stigma-management* includes techniques to keep the stigma out of the focus of the interaction. With regard to communication between aphasics and their spouses, the following questions will be addressed: firstly, how do aphasics keep the stigma, i.e. their verbal deficits, out of the focus of the communication? Secondly, how do their relatives respond to these strategies?

Introduction

Speaking is not a socially neutral enterprise. Aphasics experience the truth of this sentence as often as they are confronted with deprecatory and discriminatory reactions to their faulty verbal output by e.g. taxi drivers or sales-persons. What has always appeared strange to me as a speech and language therapist is that relatives of aphasics - who should know better - join in on this insulting behaviour when interacting with their family members in public.

In this paper, Goffman's notion of *stigma* will be employed as a theoretical framework for analysing instances of relatives' behaviour that relates to this social reality of the aphasia. Although Goffman concentrates on the (verbal and non-verbal) actions of the stigmatised person, he connects them to their relatives by stating that the *stigma*, i.e. the aphasia, spreads out in waves so that relatives of stigmatised persons acquire a degree of *stigma* (Goffman, 1963:30). With regard to the conditions of communication in aphasic families, it seems relevant to know whether the privacy of the family makes *stigma*-related behaviour superfluous or whether we find similar

patterns as described above. Goffman does not clearly state whether *stigma*-related actions are necessarily linked to publicity or not. By addressing this question, I aim to describe aspects of the social reality of aphasia that manifest themselves in verbal interaction.

Goffman's approach to deviant behaviour

Throughout his academic career, Goffman tried to establish the analysis of face-to-face interaction - a domain he entitled *interaction order* - as a field of study in its own right (Goffman, 1983:2). He succeeded. Particularly in his early studies, he concentrated on "unusual" or - in his terms - abnormal interactions, e.g. on a psychiatric ward. This extraordinary situation enables the student of interaction "to stumble into awareness" (Goffman, 1969:3).

In the context of deviant behaviour, Goffman analyses interactions between stigmatised and "normal" people. He defines *stigma* as "the situation of the individual who is disqualified from full social acceptance".¹ Goffman distinguishes between the following three types of *stigma*:

"First there are abominations of the body - the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behaviour. Finally there are the tribal stigma of race, nation, and religion, [...]". (1963:4)

Goffman terms family members of stigmatised persons *wise* persons, i.e. "persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatised individual and sympathetic with it, [...]". (1963:28). Since the family member is related to a stigmatised person through the social structure, this relationship leads the wider society to treat both individuals in some respects as one (Goffman, 1963:30). Goffman formulates two antipodal attitudes towards this ascription. On the one hand, the relative of an aphasic may be the one "before whom the individual with a fault need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as an ordinary other" (1963:28). On the other hand,

"[t]he relation between the stigmatised and his stand-in can be an uneasy one. The person with a failing may feel that reversion to type may occur at any moment, and at a time when defences are down and dependency is up." (Goffman, 1963:31)

I assume this ambivalent stance toward the stigmatised person to have a crucial impact on the interactive handling of the aphasic symptoms. The uneasiness Goffman mentions is a part of what I call the social reality of aphasia in verbal interaction. Between these two poles, the interactants may choose different behavioural patterns whereby they construct deviance interactionally.

Research design

Method

The relationship between Conversation Analysis (CA) and Goffman - until his death and beyond - was complicated, to say the least.² Nevertheless, I take the liberty to combine both approaches in order to analyse *how* (CA) and *why* (Goffman) spouses react to aphasic difficulties the way they do. In clinical linguistics, this proceeding is justified, considering the common eclectic mixture of different methods.

The main point at issue regards the distinction between system requirements and ritual requirements of interaction.

System requirements are the requirements that an interaction system must have, given that the participants have certain anatomical, physiological and information-processing capacities. Ritual requirements refer to the rules that govern interaction, given that the participants are moral beings who are governed by reciprocally held norms of good or proper conduct. (Kendon, 1988:31f)

In contrast to CA, Goffman insists that we must also have a concept of ritual requirements for a complete understanding of interaction. I agree with this. The behaviour of Mrs. A (see paragraph 4.1 below) can be accounted for solely by assuming a conflict between these two restrictive conditions.

Therefore, I will use CA methods in order to describe the system requirements of the aphasic interactions, i.e. specify how the interlocutors deal with faulty aphasic output. I will refer to Goffman's concept of *stigma* in order to describe the ritual requirements of the aphasic interactions, i.e. explain why the interlocutors deviate systematically from non-aphasic conversationalists in their verbal behaviour.

Data

The data employed in this paper are drawn from a substantial collection of video-recordings of naturally occurring verbal interactions in aphasic families, collected as part of a research project supported by the Deutsche Forschungsgemeinschaft (DFG). The project is concerned with the everyday verbal interactions of aphasics and their spouses in their homes. We hypothesize that the families adapt to the language impairment by altering their communicative behaviour - either to the better or to the worse. Ten families are asked to videotape verbal interactions which form part of their daily routine, e.g. at breakfast. The families take tapes five times: at the time the aphasic returns home from the rehabilitation centre and one, three, six and twelve months later.

All examples in the following analysis were videotaped shortly after the aphasic returning home from the rehabilitation centre. The examples were transcribed according to GAT (Selting *et al.*, 1998). The notation of gaze follows Goodwin (1981). Both aphasics in the following examples are mildly impaired amnesic aphasics.

Analysis

The notion of *stigma* as a situation implies that all persons present in this situation can control its visibility in interaction, since all of them can either ignore the *stigma* or interact in a way that focuses on it. I assume that aphasia - not as a physical impairment, but as a mark of social deviance - is interactionally constructed. In the following analysis, I will substantiate this statement by showing that as a reaction to aphasic word-finding difficulties, one spouse (Mrs. A) employs non-verbal means in order to keep the aphasia out of the focus of the interaction whereas the other (Mrs. B) uses an interactional strategy to pull it into the focus.³ Both techniques differ from what we find in non-aphasic communication when dealing with word-finding difficulties.

Reducing the tension, or: A form of stigma-management

Extract (1): A.I.1: 0.01.39-0.02.34 (18 weeks post onset)

Situation:

Mr. A and Mrs. A are sitting across the corner on the sofa. Their one-year-old son is standing between father and coffee table and throwing things off of this. Mr. A is exercising his paralytic right hand with a small elastic ring.

- 1 Fr. a: wo hast du das GELbe ding her,
 |
 nickt in Richtung Gummiring
 2 =das GRÜne da?
 ...
 |
 nickt in Richtung Gummiring
 3 Fr. a: (-----+-----+-----)
 |
 ((er schaut auf einen anderen Gegenstand))
 4 Hr. A: vom HERR [()]
 |_____||
 |
 legt Gegenstand beiseite
 5 Fr. a: [verSCHRIE]ben bekommen vom herrn
 |
 (nAme)? (-)
 |
 6 Hr. A: <<p>nein.
 7 <<f>OH
 8 SIEHST du?
 9 d' wär=es GRAD
 10 grad WÄR=es wieder, (-) HIER.
 11 ((reicht Fr. a den Gegenstand))
 12 Fr. a: ((legt Gegenstand auf den Tisch))
 13 Hr. A: <<p>das ist
 14 <<f>ja STELL es nicht hier hin.
 15 Fr. a: ja;
 16 ich NEHM es dann mit,
 17 Hr. A: <<f>ja: aber> <<decr>NICHT bis so:>

- 18 Fr. a: (-----+-----+---)
|-----+-----+-----|
|-----|
- 19 Hr. A: den HAB ich vom herrn
Fr. a: |-----|
|-----|
trinkt
leichte Kopfbewegung zu ihm hinter der Tasse
- 20 Hr. A: (-----+-----+-----)
|-----+-----+-----|
|-----|
knetet auf dem Ring herum, gleichzeitig
Lippenbewegungen
- 21 Fr. a: -----
Hr. A: <<len>gnitSCHEICha oder (wecher)
Fr. a: |-----|
- 22 Fr. a: Tasse vom Mund weg, gleichzeitig rechte Hand zum Kopf
oh GOTT. dieser SCHRECKliche name,
|-----+-----|
-
- 23 Hr. A: =<<p>ja
24 Fr. a: =(also nein);
|-----|
|-----|
reibt sich mit der Hand durch das Gesicht
- 25 Fr. a: das [WEISS] ich jetzt auch nich;
26 Hr. A: [das]
27 Fr. a: das war was POLnisches oder?
.....
- 28 Hr. A: ja: das WAR der;
|-----|
nickt
Fr. a: '''
|-----|
|-----|
stellt Tasse auf den Tisch
oder d' (-) das IST der,
29 Fr. a: |-----+-----|
|-----|
setzt sich anders hin
(-----)
- 30 Hr. A: ((knetet auf dem Ring herum))
Fr. a: ((schlägt einen Katalog auf))
31 Hr. A: WAS ist das.
Fr. a: |-----|
- 32 blättert im Katalog
(1.0)
33 Hr. A: <<p>der
34 Fr. a: ((räuspert sich und blättert))
35 Hr. A: IST das,
36 (3.4)
37 Fr. a: na ja; der ERgotherapeut
|-----+-----|
|-----|
sitzt über den Katalog gebeugt
38 Hr. A: der ERgotherapeut.

Translation:

- 1 Mrs. A: where did you get that yellow thing from,
((nods at the elastic ring))
- 2 the green one there?
((nods at the elastic ring))
- 3 Mr. A: ((looks at another object))
- 4 from mister
((sets down the object))
- 5 Mrs. A: prescribed from mister (name)?
- 6 Mr. A: no
- 7 oh
- 8 you see?
- 9 d' it would be just
- 10 it would just be here again
- 11 ((gives Mrs. A the object))
- 12 Mrs. A: ((sets the object on the table))
- 13 Mr. A: that is
- 14 yeah, don't put it here
- 15 Mrs. A: yeah
- 16 I'll take it with me then
- 17 Mr. A: yeah, but not until so
- 18 Mrs. A: ((drinks))
- 19 Mr. A: I got it from mister
- Mrs. A: ((gentle head movement towards him from behind the mug))
- 20 Mr. A: ((fumbles around with the ring, at the same time lip movement))
- 21 gnitSCHEICha or (wecher) [phonemic paraphasia]
- Mrs. A: ((removes the mug from her mouth, at the same time right hand to head))
- 22 Mrs. A: oh god. that awful name,
((rubs her hand across her face))
- 23 Mr. A: yeah
- 24 Mrs. A: (well no)
((rubs her hand across her face))
- 25 Mrs. A: i don't [know] that now either;
- 26 Mr. A: [that]
- 27 Mrs. A: it was something polish, right?
- 28 Mr. A: yeah it was the
((nods))
- Mrs. A: ((sets the mug on the table))
- 29 Mr. A: or d' that is the
- Mrs. A: ((changes her sitting position))
- 30 Mr. A: ((fumbles around with the ring))

- Mrs. A: ((opens a catalogue))
 31 Mr. A: what is that.
 Mrs. A: ((flips through the catalogue))
 32 (1.0)
 33 Mr. A: the
 34 Mrs. A: ((clears her voice and flips the pages))
 35 Mr. A: is that
 36 (3.4)
 37 Mrs. A: well; the ergotherapist
 ((sits bent over the catalogue))
 38 Mr. A: the ergotherapist

Goodwin and Goodwin point out that a word search is an *activity* in conversation analytic understanding (Goodwin & Goodwin, 1986:52).⁴ Different activities require different types of coparticipation that are organized mainly via gaze (Goodwin, 1981:10). In the extract, the word-finding difficulty arises in 1.20. After having produced a wrong name in 1.4 and having refused a candidate solution for the name of his ergotherapist by his wife in 1.6, he thinks silently for 2.6 sec, simultaneously moving his lips. This lip movement contextualizes ongoing word search.⁵ His wife looks at him during this word search. Afterwards she tries to help him by adding that the name of the therapist sounds Polish (1.27). Mr. A continues the word search in 1.28. Simultaneously, Mrs. A withdraws her gaze and - furthermore - opens a catalogue lying on the table and starts flipping through the pages (1.28-34). Goodwin and Goodwin state that during word searches, recipients characteristically gaze toward the speaker (1986:53f). This is what Mrs. A did first. Then she averts her gaze although the word search is still going on. With regard to her participation status, this indicates a display of disengagement that is intensified by her flipping through the catalogue. Goodwin notes

“that a display of disengagement treats someone who is physically present as in a certain sense not relevantly present, that is, not the subject of observation or a locus for joint, collaborative activity.” (1981:96)

Although Mrs. A is explicitly displaying non-orientation toward her husband, she is in fact paying close attention to his ongoing word search (Goodwin 1981:10). She demonstrates this to both her husband and the analyst by solving the word search in 1.37. Since Mr. A changed his search from the name of his therapist to his job's name (1.31), she had to monitor his utterances closely in order to pick up on this change of target item.

Directing the gaze toward the speaker when the recipient recognizes word-finding difficulties belongs to the system requirements of spoken interaction. In doing so, the recipient can judge whether the speaker is trying to solve this problem on his own or whether he is looking for help. I argue that Mrs. A disregards this system requirement in order to meet a ritual requirement, that is, to keep the aphasia out of the focus of the interaction whenever possible. By splitting her verbal and non-verbal behaviour, Mrs. A achieves the paradoxical goal of solving a word-finding problem she is rele-

vantly non-oriented to. This modification of behaviour is not unproblematic. In our data, there is at least one instance of annoyance on Mr. A's side because he perceives her display of disengagement as her literally not listening. Consequently, interactional adaptations have to be ratified by all conversationalists to prevent them from being interpreted in the same way as in non-aphasic communication. In that context, gaze aversion during a word search would indicate not tact, but impoliteness.

Goffman coined the term *stigma-management* for techniques that keep the *stigma* out of the focus of the interaction. When a stigmatised person interacts with persons who know about his or her *stigma*, he or she has to manage tension,

“that is, to make it easier for himself and the others to withdraw covert attention from the stigma, and to sustain spontaneous involvement in the official content of the interaction.” (Goffman 1963:102)

Although Goffman ascribes techniques of *stigma-management* exclusively to the stigmatised person, the behavioural pattern of Mrs. A as described above can also be regarded as *stigma-management* because both the procedure and the ritual goal correspond.

Amplifying the tension, or: the plight of the discredited

In the preceding example, the non-aphasic spouse displayed non-orientation to the word-finding difficulties of her husband. In the following example, the spouse displays non-understanding as a reaction to her husband's seeking for help in his word search.

Extract (2): B.I.2: 0.23.02-0.23.27 (15 weeks post onset)

Situation:

Family B is sitting at the kitchen table for dinner. Mr. B with his back partially turned to the camera; left across the corner his daughter (K), right across the corner his wife. They are talking about the daughter's toys. Mr. B. has served himself a second portion of noodles and sauce.

- 01 K: geschtern hat er ja (.) der max so starwars teil
gekriegt;
- 02 Fr. b: <<pp>hm=hm>
- 03 Hr. B: ((sieht nach links, dann nach rechts auf dem
Tisch))
- 04 ((er zeigt nach rechts auf den Tisch))
- 05 ((er stützt den Kopf auf die rechte Hand))
- Fr. b: |—————|
- |
blickt zu der Stelle, auf die
er gezeigt hat
- 06 Hr. B: <<p>(noch e BISSle)>
- Fr. b:
.....
- 07 Fr. b: was?
- 08 K: rebecca sammelt AUCH pokemon
- 09 ((Hr. B und Fr. b sehen sich an, 3.6 sec))

- 09 ((Hr. B und Fr. b sehen sich an, 3.6 sec))
 10 Hr. B: <<lachend>(nühs partesei)>
 Fr. b: '' ''
 11 Hr. B: =[lacht '']
 12 Fr. b: =[wAs soll ich dir] GEBen?
 13 Hr. B: ((neigt Kopf))
 14 Fr. b: ((dreht Kopf zu ihm, lächelt))
 15 Hr. B: parmeSON?
 16 Fr. b: [((lehnt sich zurück))]
 Hr. B: [lacht '']
 17 Hr. B: ((lehnt sich lachend zurück))
 Fr. b: '' ''
 18 Fr. b: ((schnalzt mit der Zunge, nimmt gleichzeitig den Parmesan in die rechte Hand und hält ihn hoch))
 19 Fr. b: <<staccato><<f>PAR ME>
 '' _____
 20 Hr. B: PArmesan;
 Fr. b: |_____|
 |
 gibt ihm die Käsedose, wendet Blick ab
 21 Fr. b: geNAU.
 |_____|
 |
 nickt vor sich hin

Translation:

- 1 K: yesterday he got yeah (.) max got so a starwars piece
 2 Mrs. B: hm=hm
 3 Mr. B: ((looks to the left, then to the right of the table))
 4 ((gestures to the left of the table))
 5 ((he puts his head in his right hand))
 Mrs. B: ((looks over to the spot he pointed at))
 6 Mr. B: (a little bit more)
 7 Mrs. B: what?
 8 K: rebecca collects pokemon too
 9 ((Mr. B and Mrs. B look at each other, 3.6 sec))
 10 Mr. B: <<laughing>> (nühs partesei) [phonemic paraphasia]
 Mrs. B: ((averts gaze))
 11 Mr. B: =[laughs '']
 12 Mrs. B: =[what should I give you?]
 13 Mr. B: ((tilts his head))
 14 Mrs. B: ((turns her head towards him, smiles))
 15 Mr. B: parmeSON
 16 Mrs. B: [((leans back))]
 Mr. B: [laughs '']
 17 Mr. B: ((leans back laughing))
 18 Mrs. B: ((makes a clicking noise with her tongue, at the same time takes

- 19 the parmesan in her right hand and holds it up))
 19 <<staccato>><f>PAR ME>
 20 Mr. B: PARmesan;
 Mrs. B: ((gives him the cheese container, looks away))
 21 exactly
 ((nods))

In 1.4, Mr. B gestures towards an item on the table that is placed at the right hand side of his wife and beyond his reach. Mrs. B gazes towards the item. When Mr. B starts speaking, she starts looking at him (1.6). Adopting the interpretation of Goodwin and Goodwin that non-gazing recipients start to move their gaze toward the speaker when a word search begins (1986:54), I assume that Mrs. B perceives the non-verbal request as such as a word-finding difficulty. This is not a matter of course. Mr. B so far has not produced the usual signals of speech perturbations. In 1.6, Mr. B utters 'a little bit more' which could be completed by a noun phrase but does not have to in order to be grammatically correct. Mrs. B reacts by asking 'what?' Then a long silence (3.6 sec) follows in which the couple simply looks at one another. In this way, they contextualize this other-initiated repair as something special. In 1.10, in realizing that his wife is not going to help him, Mr. B produces a phonemic paraphasia. Thereby Mr. B shows that he no longer expects a response from his wife. In 1.12, Mrs. B repeats her repair initiation, this time in fully-fledged form. Mr. B produces another paraphasia. In 1.18, Mrs. B takes the cheese and then tries to prompt his correct pronunciation. She closes this language-relearning lesson by saying 'exactly' after her husband was finally able to pronounce 'parmesan' correctly.

In other words, by moving her gaze toward her husband Mrs. B displays attentiveness, but no more. In order to describe her interactional behaviour afterwards, I adopt Wagner's distinction between *substantive* and *formal* understanding (Wagner, 1996:232). I term her behaviour *formal non-understanding*, i.e. although she knows what her husband has asked of her, she acts as if she does not. The upshot of my argument is that an analysis that restricts itself to the system requirements of verbal interaction cannot make sense of the episode above. Mrs. B's sponging off the repair-initiation format has nothing to do with its use in non-aphasic communication since it does not secure or restore mutual understanding. Quite the contrary, instead of stretching her meaning creating potential to the limit which is what participants in spoken - both non-aphasic and aphasic - interaction generally do (Wagner & Firth, 1997:342), Mrs. B shrinks hers. Consequently, by puffing the aphasic deficit up, Mrs. B does not reduce, but rather amplifies the tension that accompanies the *stigma*.⁶ Overt sign of the tension is the constant embarrassed laughter of Mr. B by which he contextualizes his attempts to pronounce 'parmesan' correctly (1.10ff). For this situation, Goffman coined the term "plight of the discredited" (1963:4).

Discussion

Aphasic communication is different. Gaze aversion does not necessarily mean non-cooperation or lack of interest. On the other hand, gazing toward the speaker during his word search does not imply cooperation in solving this problem. What is more, other-initiated repair does not always indicate handling a problem of understanding resulting from the aphasia. Using the conversation analytic approach on procedures that participants apply to word-finding difficulties in interaction, one can describe these differences between aphasic and non-aphasic communication. But why do they do this? I would suggest that participants in aphasic communication adapt to the needs of their special situation, i.e. the *stigma*, by giving priority to its ritual requirements. This means violating the system requirements of spoken interaction. As the analyses have shown, the non-aphasic spouses behave differently with regard to the aphasic difficulties of their husbands. Goffman's dynamic notion of *stigma* as a situation is capable of dealing with these variations. This is the meaning of the term "social construction of aphasia". The spouses have the option to control the amount of interactional space the aphasia is given during the conversation. In addition, they do not have to use techniques of *stigma-management*, whereas the stigmatised persons do in order to act as competent social agents. This asymmetry of behaviour mirrors the asymmetry of power in the interaction. With regard to this imbalance, I would strongly recommend a conceptual distinction between *face-work* (Goffman, 1955) in "normal" interactions and *stigma-management* in deviant situations. The central feature of *face-work* is its reciprocity. On the contrary, the Golden Rule "Do unto others as you would have them do unto you" is not valid in "abnormal" encounters. The possibility of linking interactional patterns of the spouses to *stigma* shows that this situation is not necessarily bound to publicity. It governs behaviour in the privacy of the family as well.

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Nederlandse samenvatting

Gedurende de laatste jaren is binnen het afasiologisch onderzoek het accent verschoven van de cognitieve naar de communicatieve en psychosociale aspecten van afasie. Deze dimensies van chronische ziekte zijn vastgelegd in de Internationale Classificatie van Stoornissen, Beperkingen en Handicaps (ICIDH-2), ontwikkeld door de Wereld Gezondheidsraad. In termen van de ICIDH-2 verwijst *participation* naar de invloed van de ziekte op de betrokkenheid van de patiënt bij situaties in het dagelijks leven. In dit artikel pas ik Goffmans begrip *stigma management* toe in de afasie. De stelling is dat dit begrip zinvol is voor het beschrijven en analyseren van processen van sociale desintegratie, dat wil zeggen de Participatie als gevolg van een gebrekkig taalgedrag in de persoonlijke interactie. Volgens Goffman omvat *stigma management* technieken om het stigma buiten de focus van de interactie te houden. Met betrekking tot de communicatie tussen afasiepatiënten en hun echtgenoten komen de volgende vragen aan de orde: ten eerste, hoe houden afasiepatiënten het stigma (hun verbale tekortkomingen) buiten de interactie?; ten tweede, hoe reageren hun partners op deze strategieën?

Notes

- 1 The concept of *situation* is central to Goffman's approach. (see Goffman, 1964) Conceptualizing *stigma* as 'situation' makes it possible to account for different interactional patterns by all interlocutors in dealing with the aphasia.
- 2 Cf. Auer, 1999:148f; Bergmann, 1991; Drew & Wootton, 1988; and - particularly acerbic - Schegloff, 1988.
- 3 Due to shortage of space, the analysis is limited to two interactional strategies with contradictory effects. In our data, we have found others as well. The selected procedures are prototypical insofar as keeping the aphasia out of the focus of interaction is achieved primarily by non-verbal means and the opposite chiefly by verbal ones.
- 4 For *activity* in CA cf. Schegloff, Ochs & Thompson, 1986:21f.
- 5 For the concept of contextualization cf. Auer, 1996.
- 6 At the beginning of the dinner during which the episode analyzed took place, Mrs. B asked her husband 'what is this?' when he shuffled parmesan onto his noodles. He produced phonemic paraphasias as an answer either.

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