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'Would you like to use one of these or would you rather be able to talk?' – facilitated and/or augmentative communication and the preference for speaking

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This article examines the concepts of identity and personhood in relation to people with severe communicative disabilities. Data gathered at a Swedish day centre for people with acquired brain damage show that three main strategies in communication between able-speaking and impaired-speaking persons can be found: (1) perfunctory, (2) jigsaw puzzle, and (3) conjectural, all three strategies being based on the act of *speaking*. This article shows why it seems important to talk with one's own physical voice instead of using augmentative and/or facilitated communication, even when one has a highly impaired speech pattern. I argue that an ideology of spoken language exists within western culture and that such an ideology has practical implications for the (re-)creation of meaning-making strategies in relation to people with severe communicative disorders. Implications for health-care personnel working with communicatively impaired people are also identified, as well as implications for researchers studying this field of interest.

Keywords: communicative strategies; disability; ideology of speech; personhood; identify

A voice means this:
there is a living person, throat, chest, feelings, who sends into the air this voice, different from all other voices . . .

(Cavarero 2005, 4)

Introduction

Excerpt 1 (transcript key is found at the end of the article)[1]

Eleonor:	Do you like to use the LightWRITER?
	[communicative augmentation aid]
Pete:	[shakes his head] No.
E:	No, I think I have noticed that (.) you prefer to speak don't you?
P:	Yes
E:	How come?

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P: Would you [points at me] like [I look a bit bewildered, leans in towards him] (.)
Would ... you ... like ... to ... have ...
E: One of these [points at the LightWRITER]
P: or [xxx xxx]
E: One more time (.) If I would like to have one of these?
P: or
E: or rather be able to talk?
P: [does a thumbs-up to show that I have understood correctly]
E: Well, that's really hard for me to say since I can talk [Pete laughs heartily] but well (.) seeing that you used to talk [Pete nods] right? [Pete nods] then (.) that's what you'd rather do?
P: Yes

Pete, a young man in his late 20s, suffers from severe disabilities due to brain damage he acquired in a car crash in his adolescence. I am interviewing him and we discuss that he does not seem particularly interested in using his communicative augmentation aid. Our conversation springs from the fact that I have conducted a nearly one-year-long field observation prior to this conversation (where Pete was one of my key informants). This is not the first time we discuss these things and what probably seems to be quite leading questions is rather a continuation of earlier discussions. Hence, I would say that Pete's position is clearly outspoken and his question to me, *would you like to use one of these* [the LightWRITER] *or would you rather be able to talk*, sums it up elegantly; his preferred way to communicate is to *talk*. One question that then arises is *why*? Why is it so important to be able to talk, to speak with one's voice instead of using facilitated and/or augmentative[2] communication?

It has been argued that people who suffer from severe disabilities due to acquired brain damage often face new challenges in their lives. Disability as a consequence of trauma has for ever altered their lives and issues revolving around identity and personhood are (re-)addressed in new, and often complex, ways (Antelius 2007, 2009; Mattingly 1994, 1998). Not only has the brain damage led to severe physical disabilities but often it results in communicative disorders as well. The persons with brain damage are often forced into new ways of communicating when they can no longer use their speech as they used to. Whether these communicative disorders consist of aphasia, explicit aphasia, loss of speech altogether, slow or guttural speech patterns, or anything in between, it seems that such a communicative disorder puts a severe strain upon both the person with the disorder and their communication partners. For the person with the brain damage it can be extremely stressful to be able to utter even the shortest of sentences (if they are even able to put their words into sentences). It also seems just as hard for the communicative partner to try to understand and respond properly to the person with the communicative disorder.

In order to try to minimize these strains many augmentative communication aids have been invented and put into use. However, I will show in this article that there seems to exist a preference for speaking with ones own voice; using augmentative and/or facilitated communication always seems to be a second choice (if it is even a choice at all). This strong preference for speaking is intriguing and extremely important to understand because it implies not only that we have and use languages in order to communicate with each other, but also that there exist ideologies about language use. And such ideologies lead to practical implications in relation to issues

revolving identity and personhood since these are issues that are established mostly in spoken communication and relations with other people.

Ideologies of language

It has been argued that in order to understand how we as humans create our social and cultural world, we need to pay close attention to the employment of language (Ochs 1988; Schieffelin and Ochs 1986; Schieffelin 1990). Hence we need to study language not as a system of its own but rather as a constitutive feature of social life (Gumpertz and Hymes 1972; Duranti and Goodwin 1992). It then also becomes crucial to pay close attention to the fact that there is as much cultural variation in ideas about language as there is in speech forms themselves. Notions of how communication works as a social process and to what purpose are culturally variable and need not be taken for granted, or simply assumed; they need to be discovered (Woolard and Schieffelin 1994, 55). The ideologies of language are thus significant for social analysis, because they are not just about language. Rather, such ideologies envision and enact links of language to group and personal identities as well as they underpin fundamental social institutions – as Williams stated, 'a definition of language is always implicitly or explicitly, a definition of human beings in the world' (Williams 1977, 21). Hence, language ideology stands in relation to, and shapes, social practices (Schieffelin, Woolard, and Kroskrity 1998). It is thus what Hymes called for when he argued that the cultural conceptions of language should not be taken for granted, nor should language be perceived as something neutral (Hymes 1964, 1974). Rather, as an ethnographer of speaking, one should study language as a key (cultural) idea about personhood where language is regarded more as an interactional resource (connected to issues of power) than a shared cultural background (Woolard and Schieffelin 1994, 60).

Thus, this article examines what such a rediscovery of an ideology of language might reveal about the power relations between able-speaking and impaired-speaking persons when there, as the data will show, seems to exist a preference for speaking. Hence it aims to examine what I have called *the ideology of spoken language*;[3] where I use *ideology* to show that:

> The term ideology reminds analysts that cultural frames have social histories and it signals a commitment to address the relevance of power relations to the nature of cultural forms and ask how essential meanings about language are socially produced as effective and powerful. (Woolard and Schieffelin 1994, 58)

And *spoken language* because:

> [I]t would seem inescapably obvious that language is an *oral phenomenon*. Some non-oral communication is exceedingly rich – gesture for example. Yet in a deep sense language, articulated sound, is paramount. (Ong 1982, 6–7, my emphasis)

And

> The spoken word is a medium, a trace whose evanescence in time and space is compatible with the preservation of meaning. (Giddens 1991, 23)

Further, this ideology of spoken language will be analyzed in relation to how both communicative and meaning-making strategies (especially identity-/personhood-making processes) are affected when someone suffers acquired brain damage and

is forced to communicate in new ways. Hence, I wish to not take language for granted but rather to (re-)discover it and its possible meanings.

Mutual communicative problem solving

Communicative acts must, of course, always be understood within the contexts in which they occur. It is important to point out then, that this article is based upon material gathered in an institutional context where most of the people cannot speak unimpeded. As such, the communicative acts in this context probably differ from other communicative acts. However, as in all communication, whether between able-speaking and able-speaking or between able-speaking and impaired-speaking persons, it is crucial to remember that communication is always (at least) a two-way street. Therefore, we need to pay attention to the *joint* construction of meaning between the communicative partners; in order to understand how meaning-making processes can occur within the framework of the situation, we need to focus upon both parties in the conversation.

It might seem trivial to mention such obvious things but I urge everyone to keep this in mind since one of the key ideas of interactionist social theory is that the origin of the self is social, in that it is guaranteed through social interaction (Goffman 1959; Kontos 2004). To conceptualize personhood could then be said to be to place '... the human being in relation to others' (Kitwood and Bredin 1992, 275). This has crucial effects on how we perceive the concept of personhood since this is then something that gets created between people; i.e., personhood is relational and contextually bound (Harré and Secord 1976). As such, the institutional context that I have observed might set its own special framework upon the communicative acts and thus also how identity and personhood are created within these acts. However, as Durkheim and others have shown us, even a study of the extreme could tell us something about the general. Hence, I wish to argue that since identity/personhood is created and guaranteed through social interaction, a study of these concepts in a context like the one that I have observed will also be able to tell us something about the ideologies of language and these ideologies implications on our notion of the concept of identity/personhood in general. Perhaps this is especially so since even though this is an institutional context the communicative acts are not so-called institutional meetings (e.g., Karlsson and Hydén 2007; Drew and Heritage 1992). Rather, they are everyday conversations.

The Boost and its people

During 2004 and 2005 I spent most of my time at a day centre for people with severe disabilities[4] due to acquired brain damage. The Boost (as I have chosen to call it) offers individually adapted activities for the participants. The participants are a heterogenic group of people with the youngest participant being 28, the oldest 64. There are some 20 participants at The Boost, men and women, of mostly Swedish origin. They attend the day centre and receive training according to how much is considered suitable for each individual participant (ranging between half a day to four days a week). Training is mainly physical but also communicative. It is, however, not considered to be rehabilitation since the participants are considered medically incurable. Thus, the day centre is said to be a daily activity rather than a rehabilitation centre. As such it strives to offer the participants daily activities

adjusted to their personal needs in order to maintain their present functions and skills rather than to improve them.

The participants have all been labelled as having severe disabilities due to acquired brain damage, however, the stories behind the brain damage are as many as there are participants at the day centre. There is the young man who at the age of 15 took his family's car out for a drive and crashed; the other young man who drove under the influence of alcohol and drugs and crashed; the woman who was first in one car accident, was completely rehabilitated and then was involved in another car crash; there is the man who was working on a roof and fell off; the man who drank too much; the man who used to much drugs; the man who had just married and on a holiday dove straight onto a rock at the bottom of the sea; and the man who was assaulted and received a severe blow to the head. And then there are those who have acquired their brain damage due to medical reasons such as the several cases of stroke; the woman who went into a diabetes-related coma; the man with MS; the woman with MS; the woman with Huntington Chorea; and finally the anorexic man who starved himself into a brain seizure.

As such, the participants had various kinds of brain damage and they ranged in terms of disabilities (even if they were all considered severe and were often labelled as a group of severely disabled people). Some were in self-manoeuvred wheelchairs, some in wheelchairs manoeuvred by others, some walked on their own, and some walked with the aid of others. Others were paraplegic, some had partial paralysis of the upper and/or lower body, some had uncontrolled body movements. Communicative disabilities ranged between explicit aphasia, slow, or guttural speech patterns to having no (oral) speech at all. Some spoke almost fluently.

The personnel consisted of seven assistant nurses, one physiotherapist, and one occupational therapist. The therapists came in once every now and then since they also worked with other day centres and some sheltered houses, while the assistant nurses often worked on a close one-on-one, everyday basis with the participants.

Gathering of data

As the personnel aimed at working with the participants on a one-on-one basis, I soon realized that I was perceived as quite out of place when I positioned myself as a bystander. Hence I gathered my material by being a *participant* observer, involving myself in all of the daily activities and having close personal relationships with a few of the participants. Since my material thus is based to some extent on my subjective relationships with both personnel and participants I felt that several methods of gathering data were needed in order to try to triangulate[5] my data; including participant observations and the writing of field notes, video recordings and informal interviews with both personnel and participants. Participant observation were conducted throughout the entire year and during the last months I also recorded about 70 hours of film, where all aspects of the day centre were filmed (except toilet visits). Filming, however, was not random. I followed each of five participants more closely for one week at a time. Thus the focus was on one participant at a time, although all participants were filmed as they had many joint activities.

Interviews were conducted towards the end of my fieldwork (when I had come to know them all quite well). I interviewed seven staff members and five participants. The participants I interviewed, including the two young men, the woman with MS, the woman with Huntington Chorea and the man who had fallen off a roof, were all

people that I had come somewhat closer to than I had to the rest of the participants and they were all people who had speech patterns that I as a researcher had learnt to understand. In order to try to show my main argument in this article – that there exists an ideological preference for speaking with ones voice and that this affects our notion of the concept of personhood – I base this article on all forms of my data.

Ethical considerations

I have followed the procedure demanded by Swedish law, in that all persons included in the study should be asked for informed consent for all parts of the study (observations, interviewing and videotaping). However, in some cases it was uncertain if the consent could be truly informed. A few of the participants had severe cognitive brain damage and impaired short-term memory, meaning that sometimes they did not remember me and why I was present at the day centre. Therefore, all the participants' legal guardians (in Swedish *god man*) were also asked for informed consent. All participants, legal guardians and personnel agreed to the study.

Three communicative strategies

I set out to do this project open to any insights that would cross my path. I did not start out with a hypothesis that I wished to confirm or disprove. Instead my main goal was to try to understand what everyday life could be like for people who have suffered acquired brain damage. Simply put, it was to explore the everyday world of the chronically ill and disabled, which is often neglected in research (Barnard 1995, 38ff.). Hence, during my first months of participant observations, the preference for speaking was not something that I thought about at all. Frankly, I was mostly fascinated by the fact that the personnel and the participants seemed to understand each other at all since I had such trouble understanding some of them myself.

This however slowly changed over time when I myself learned to understand the participants and then also started to notice that yes, the personnel *seemed* to understand the participants, but did they *really*? Often some of the participants would scream (or the opposite, go completely silent) and they seemed frustrated in their communication with the personnel. This caught my attention and I decided that one part of my study needed to focus upon the actual outspoken communication between the participants and the personnel. Did they understand each other by speaking to each other? And, if not, why did they focus so much upon speech; why not use the augmentative communication appliances they had at their disposal? I became more attentive to this interesting phenomenon, started to categorize my data, looking for re-emerging patterns and structures within my empirical observations, my interviews and my video recordings. What I found was that there seemed to exist (at least) three main communicative strategies between the able-speaking and impaired-speaking persons: (1) perfunctory; (2) jigsaw puzzle; and (3) conjectural.

These three strategies are based upon what I observed at the day centre. Hence, they are not analytical scientific concepts that I have first identified (through literature) and then looked for in the situations; the empirical findings came first. It is thus in line with Goode's idea that:

> the way that people construct the social activities of their everyday lives is not in satisfaction of scientific versions or theories of phenomena [...] Everyday phenomena are constructed in an orderly way by those who live them, with or without the existence or conduct of professional research. (Goode 1994, 49)

The communicative acts that I studied would (probably) be the same, even if I as a researcher were not there to study it. The people in this study make their choice to use spoken language in relation to their lived life-world, not by engaging in theoretical arguments. That, however, does not mean that we cannot *use* scientific analytical theories in order to try to understand those choices. I will argue that in order to understand why a person who suffers from severe communicative disorders prefers to use his/hers voice in order to try to create meaning in situations, we need to also understand that there seems to exist an ideology of spoken language.

It is also crucial to remember that even though I present only a few examples of each strategy this is not something that happened on a few rare occasions; my examples and the strategy theory I will present are what I believe to be the core of the everyday situation at the day centre. I present a few situations and analyse them, however, there where plenty of other situations that could have been analysed. I have chosen these particular situations because they are representative and display the everyday situations within The Boost quite clearly.

I have chosen to call them *strategies* (rather than perhaps patterns/structures) since I argue that there exists an intentionality behind these strategies. They are more than just patterns; they are long-term, overall modes of procedure. As such, they are methodical modes of procedure adapted to the situation. Hence they are communicative strategies rather than patterns or structures because they have proven to be the communicative acts that seem to work in the interaction between the personnel and the participants in this particular setting.

Let us now turn to some examples of these three strategies in order to show that these strategies can be related to the idea that there exists an ideology of spoken language. By doing so we will also in the end see what consequences might be derived from such a fact; what are the *practical implications* for meaning-making processes within the framework of the situation if there exists a preference for the spoken language? And how may that affect our perception of the idea of identity/personhood?

Perfunctory strategies

In my empirical observations I have found that the personnel and the person with the brain damage create a sense of meaning together in their communication through *perfunctory strategies*, where the speech of the impaired-speaking persons seem to work as a signal into cut-and-dried responses. During my one-year fieldwork at The Boost, I observed several procedures that recurred on a daily basis. These procedures usually reflected what the participants wished to do and/or what they wanted. In one case there is a middle-aged lady, Judith, who due to a car accident has lower-body paralysis and an impaired speech pattern. Everyday she goes through the same procedure of telling the personnel that she wants two napkins with her lunch and she wants cold water poured in her cup of coffee before the coffee is poured in. On 9 April 2004 I wrote in my field notes:

> Judith always wants napkins with her lunch (instead of the bib that most of the other participants uses), and she always tells the personnel this far in advance so that she has

> her napkins by her side long before lunch is served (the napkins are really pieces of torn kitchen paper). This procedure gets repeated every day, as does her procedure of asking for cold water being poured into her coffee cup before coffee is poured into it. Every day, it seems, the same repetitive procedure/request.

These two requests are very important to Judith; when she does not get her will she screams, violently. But she usually succeeds in making her request heard/understood. However, this successful communication is based upon endless repetition. The personnel do not listen so much to what Judith actually says (since it can be very hard to understand due to her speech pattern) rather, they have learnt what she wants and assume that they know what she says. Usually they get it right and Judith is satisfied. A similar case involves Charles, who wishes to pour his coffee into his own cup, rather then having it poured for him. On 22 September 2004 I wrote:

> Charles wishes to pour the coffee into his own cup but because of the weakness in his upper arms he does not have the strength to lift either the pot of coffee or the carton of milk (without the risk of spilling it). The personnel have solved this by pouring coffee and some milk together in a special container which Charles can manage to lift. Charles can then pour his own coffee into his own cup.

As in the case regarding Judith, this successful communication also builds upon the routine between the personnel and Charles. This became apparent one day when a new assistant nurse, Eia, joined the day centre and could not understand what either Judith or Charles said. When serving Charles his coffee she poured it straight into his cup, which led to Charles being extremely angry; he deliberately knocked over his cup at the same time as he shouted at her. And later, when Eia did not understand what Judith said (she wanted her napkins), Judith started to scream furiously and Maud, another assistant nurse, had to come and help.

What these two examples show is that the speech seems to trigger off certain practices/events; what is *actually* said is not that important (often the personnel cannot hear this). Rather, they know what is about to be said and act according to that. For instance, Eia quickly learned that Judith wanted her napkins and Charles wanted his coffee poured into a special container. Eia still could not understand what they said (she told me so) but learnt what they (usually) wanted and acted according to that. One could then talk about the speech as setting off a chain reaction of events, events that are acted out as a perfunctory strategy.

The jigsaw puzzle strategies

Another strategy that was used could be compared to laying a *jigsaw puzzle*, where the communicative partners needed to hook their pieces of speech into one another, thus creating a whole. However, when one of the partners in the communicative act suffers from a communicative disorder, more stress is put upon the able-speaking person to be able to connect the pieces into a whole. To solve the puzzle all the different pieces of speech need to be connected, otherwise the whole cannot be achieved, and hence it becomes hard (sometimes even impossible) to create a sense of joint meaning within the situation.

Pete (introduced in the beginning) is a young man, in his late 20s, and he suffers from brain damage due to a car accident in his adolescence. Today he is still in a wheelchair, with a lower body paralysis. Pete does not suffer from any cognitive damages or aphasia, however, his speech pattern has changed dramatically and today

his speech is guttural and it is often very hard to understand what he says. Hence, Pete also uses the aid of a LightWRITER. The following example is also from the interview I did with Pete. We have been talking for about 30 minutes when we enter the subject of friends:

Excerpt 2

Eleonor: Do you have any friends and stuff that you hang around with?
Pete: Yes, one.
E: Jon? [P nods] What do you usually do then?
P: [xxx]
E: Just? No
P: [xxx]
E: [points at the LightWRITER] Do you feel like writing?
P: [does not write, but points at the letters] T . . .
E: Talk? [P nods] Just talk to each other?
P: Yes
E: What do you talk about then?
P: Everything [xxx] [xxx]
E: No:o (.) now I couldn't quite follow
P: [points at the LightWRITER] a . . . d . . . u
E: Adult chat? Adult talk? [P shakes his head]
P: Adult[xxx]
E: Adult (.)?
P: f . . . r . . . i . . . e . . . n . . . d . . .
E: Adult friend?
P: Yes
E: So you talk about adult stuff?
P: Mary (.) Mary [on the videotape this is heard quite clearly, however I did not hear it during the interview]
E: Once more (.)
P: M . . . a . . . r . . .
E: Mar?
P: y.
E: No:o (.) can you write it. I didn't quite follow.
P: [Turns on the LightWRITER and writes:] Mary
E: Mary? Uhum. Who's Mary?
P: My big sisters
E: Your big sister?
P: No
E: Little sister?
P: No
E: Big sister?
P: Big sisters [Pete accentuates the s at the end but this I cannot hear. Pete eventually puts on his LightWRITER and starts writing] My . . . big . . . sister
E: Uhmm, Mary is your big sister?
P: No
E: Is it Jon's big sister?
P: *Don't know if he has a big sister*.
E: Who's big sister is it? Yours? Yes, it says mine (.) my big sister, does she hang out with you?

P: No [shakes his head]
E: I'm just gonna change the tape in the camera, but you write on
[change of tape – some data lost]
P: My big sister
E: Uhmm, your big sister?
P: s
E: mm, s.
P: My big sisters
E: What was it you wanted to say about Mary?
P: My
E: That it is your big sister?
P: No
E: No?
P: My
E: My
P: Big sister.
E: Big sister?
P: s
E: s
P: My big sisters, s [Pete starts to look frustrated]
E: s? I don't quite follow Pete, your big sister S?
P: My big sisters
E: Yes, I understand that Mary is your big sister.
P: No.
E: She's *not* your big sister?
P: No [turns on the LightWRITER] my . . . (36s) my . . . big
E: Yes, your big sister? [P keeps writing] Yes (.) you've said big sister Pete.
P: No:o
E: No?
P: Big sisters
E: Aha, *now I might get it* (.) is it your big sisters kids?
P: No her [xxx]
E: Big sisters?
P: [xxx]
E: You can write that too
P: Old [xxx]
E: Old preacher? No (.)
P: t . . . e . . .
E: Teacher?
P: Teacher.
E: What about your big sisters old teacher??
P: She . . . is . . . my . . . adult friend.
E: Adult friend? *Aha*, sorry, that took a long time for me to figure out [smiles]
P: *That's ok*.
E: *Its ok?* Good. What do you and Mary usually do then?

This, I argue, is an example of communication as a jigsaw puzzle. Together Pete and I contribute one piece at a time in order to create the whole. However, much of the conversation hinges on me when Pete wishes to tell his story of his adult friend Mary. I hope that the excerpt shows the difficulty and the frustration of how hard it is to jointly create a sense of meaning in a conversation like this. I (being the able-speaking in this conversation) have to repeat Pete's words (or even each individual letter) over and over again (the . . . -markings is showing this) and as the excerpt shows, I usually

get it wrong because I do not understand his speech-patterns. Hence, following this conversational order (by repeating everything that is said in order to check if I have understood correctly) requires time, *a lot* of time (and patience).

Pete wishes to tell me about his adult friend Mary, who is his big sisters old teacher. Normally this could be told in the matter of minutes, if not seconds. Now, it takes Pete more than 20 minutes (!) to create this story together with me. I wish to argue that for Pete to tell about his adult friend, which I believe means that it is a friend he has made in his adult life, after the accident, is crucial in his story about himself as it points to the fact that he is more than just disabled. For Pete to tell me that he has an adult friend is a way for him to tell me that even though he is regarded as severely disabled he is quite capable of making new friends. And the fact that it takes him over 20 minutes to be able to do so must be seen as an impediment in his attempts to create meaning around himself, and how he sees himself as a person. In this particular situation, Pete and I eventually reach a sense of jointly constructed meaning and understanding since we were both willing to keep on. But this took time and a lot of patience from us both. And, as we will see in the following example, this is more the exception than the rule.

Conjectural strategies

The third strategy I have called *conjectural*. It may seem that this strategy is similar to the second strategy, the jigsaw puzzle, only that in the previous example the communication is successful and in this example it fails. However, I will show why I wish to argue that these are two different strategies.

The following example is from a video recording made during my last months at the day centre. Judith (the same Judith as above, with the napkins) is in her 40s. Due to a car crash several years ago she is now in a wheelchair, with an extensive weakness in her lower body (she can walk very short distances with the aid of a walking-table). However, she has full upper body strength so she manages her wheelchair on her own. She does not suffer from aphasia or cognitive damages, but the brain damage has resulted in an impaired speech pattern, making it quite hard to understand what she says most of the time. The excerpt is from a video recording in which Judith and I are sitting at a table, (trying to) talk to each other. Beth, an assistant nurse, joins the conversation:

Excerpt 3

Beth:	¤What are you talking about?¤
Judith:	I don't remember.
B:	We:ell (1s.) *you're gossiping about me of course*
J:	No (1s.) we're talking about the car accident [23 seconds pass as Beth turns towards me and tells me how tired she is and that she does not understand how she managed to work 100% before; now she only works 75%. She then turns back to Judith and starts asking about her life, before the accident.]
B:	How many years did you work at Volvo?
J:	Five years.
B:	Five years?
Eleonor:	Did you work at Volvo here in the city?
J:	Yes
E:	Aa:hh (.) what did you do there?

J: deyda digreyda [this is inaudible both in the situation and afterwards, when listening to the tape. Judith says something that sounds like deyda digreyda, neither Beth or I understand what Judith says but Judith keeps repeating the exact same sounds throughout the conversation]
B: Night watchman?
J: deyda digreyda
E: Did you clean?
J: deyda digreyda (.) deyda digreyda
E: [leans towards Judith] One more time, I cant really hear you.
J: deyda digreyda (.) deyda digreyda
E: Did you say clean??
J: deyda digreyda
B: Welding?
J: deyda digreyda
B: Weld??
J: deyda digreyda
B: [turns towards me] You know, it was some type of machine, you know, weld, punch (.)
J: DEYDA DIGREYDA
B: My God, how you scream. [covers her ears and is about to leave]
J: deyda digreyda
B: [Beth who was about to leave turns around and grabs Judith by the shoulders] But Judith, what's the matter with you? There's no reason to scream like that.
J: ¤xxx¤
B: One thinks one has made the worst mistake ever when you scream like that. [Judith goes silent and looks down at the table. Beth walks away.]

This situation is new (Judith trying to tell me something with the aid of Beth) and hence no perfunctory strategies can be used in order to do so. Neither can the jigsaw puzzle strategies be used because Beth cannot hear what Judith says and hence Beth cannot try to hook her pieces of speech into Judith's and thus lay a jigsaw puzzle of words in order to create meaning within the situation. Instead Beth tries to guess several times, Judith repeating the same words over and over but when Beth has guessed several times without getting it right Judith becomes extremely frustrated and starts screaming out the words instead, leading to Beth losing her patience and starting to walk away. When Judith then screams even louder, Beth turns back and tells Judith that there is no need for such behaviour. Judith falls silent and her attempt to tell us about her former work life failed. No joint sense of meaning was created within the framework of the situation.

This strategy differs from the jigsaw puzzle strategy even though it might seem that some part of that strategy is also based on guessing. It differs because in this conjectural strategy Beth never hears what Judith tries to say and hence she guesses wildly (even though she tries to use some perfunctory strategies as she knows that Judith used to work in a factory, with some sort of machine). In the jigsaw puzzle strategy cited earlier, on the other hand we saw that the guessing was always connected to what Pete had said. Hence, in that strategy the two communicative partners try to build a whole together by hooking their words into one another's, while in the conjectural strategy this is not the case (of course, the conjectural strategy does not always fail as in this case, sometimes it turns in to a jigsaw puzzle strategy, just as the jigsaw puzzle strategy can turn into the conjectural strategy).

The three strategies – to speak, to speak, and to speak

Above I have tried to show that there exist (at least) three main strategies of communication between the personnel (or me) and the person with brain damage, namely (1) the perfunctory strategy, which builds on routine and repetition over time; (2) the jigsaw puzzle strategy, which requires time, patience, and quite often background knowledge about the person; and (3) the conjectural strategy which is mostly based on wild guessing. We also saw that with the third strategy communication 'failed' and no joint sense of meaning was created within the framework of the situation (at least not in relation to the subject that was discussed). According to my observations, this is quite a common result in the communication between the participants and the personnel.

Yet when asked to try to use augmentative communication aids (as for instance a LightWRITER) most of the participants reject this and continue to rely on their speech as their main communicative tool. Remember how vividly Pete expressed this preference for talking in the introduction of this article. He did not want to use his LightWRITER if he did not have to (and the personnel do not seem all that eager to do so either). We must then ask ourselves *why* it is so important to speak with ones own voice when this seems so hard. Why this preference for speaking? One of the reasons that I believe we must ask us this question is because the ability to speak seems to stand out when compared to other abilities. To lose one's voice seems devastating, while losing other former functions does not. Sarah (another participant) illustrated this one day when we had been to the gym and I observed the participants playing handball together. Afterwards I asked Sarah whether she liked playing handball or not and she said that she really did not care for it any more, it was not the same thing because 'it's no longer fun when I can't walk' (Antelius 2007). It was not the end of the world, but 'it was no longer fun'.

It could be argued that the preference for speaking seems to originate from the fact that once the participants *were* able to talk and hence that is what they still wish to do. This could be thought of as a wish to be normal, to be as one once was, but I argue that it goes beyond that. The preference for speaking is not just a wish to be 'normal' but rather the wish to speak could be seen as a representation, a symbol if you like, for *the good life*, life as it once was, the life before brain damage, where one still had hope of a promising tomorrow (Antelius 2007). However, the preference for speaking does not seem to be only a representation of a good life either. It seems as if it is not as hard to give up other former abilities (such as playing handball or in fact even walking) as it is to give up speaking. To be able to speak seems to be something else, something *more*.

The ideology of spoken language

The human language, primarily the human ability to use a symbolic language, has long been said to be one of humankind's most distinguishing characteristics (Goode 1994; Kuper 1994, 78). Sacks states in his *Seeing voices* that '[l]anguage [. . .] is not just another faculty or skill; it is what makes thought possible, what separates thought from non-thought, human from non-human' (2000, 68). This specific kind of language is also thought to be primarily oral. Even if we communicate in non-oral ways as well, it seems as if what makes us unique is our ability to communicate through the spoken word. As written above, Giddens claims that '[t]he spoken word

is a medium, a trace whose evanescence in time and space is compatible with the preservation of meaning' (1991, 23). Ong went even further and claimed:

> [I]t would seem inescapably obvious that language is an *oral phenomenon*. Human beings communicate in countless ways, making use of all of their senses, touch, taste, smell, and especially sight, as well as hearing. Some non-oral communication is exceedingly rich– gesture for example. Yet in a deep sense language, articulated sound, is paramount. (1982, 6–7, my emphasis)

As stated earlier, there is as much cultural variation in ideas about language (speech) as there is in speech forms themselves and the connection between language and (oral) speech is probably not universal. It seems however to at least be present in western culture[6] where spoken language is often given a privileged position and the ability to speak with one's own voice often seems to be given preference over non-oral expressions[7] (Antelius 2009; Hydén and Peolsson 2002; Ong 1982). And with a western culture that eulogizes spoken language we find an ideologically motivated preference for speaking; your voice is your *personhood* because there exists a singularity, a uniqueness, in every voice (Cavarero 2005). Each human being's uniqueness is then embodied through his or hers voice. This is in fact what Arendt (1998) called 'the human condition' – that every persons unique personal identity is dynamic in that it gets created in relation to others, *and* that this uniqueness is expressed through our voices. Cavarero further states that 'speech is first and foremost a privileged way in which the speaker actively [...] distinguishes him- or herself to others' (2005, vii). And, as it has often been argued, that which is valued in the western world is individualism, that the self is a sovereign and independent agent. To be able to be such a sovereign, independent agent in the western world we then seem to *need* to talk, to communicate by speaking with each other, because without our voices we are not ourselves. Without our voices we seem to loose our personhood.

Consequences due to the preference for speaking

What is important to point out is that in order for your voice to be the embodied uniqueness of you, there needs to be someone who listens to your voice. There needs to be an ear catching your voice in order for it to mean anything; it implies a relationship (Cavarero 2005, 4f.). As stated earlier, communication is always (at least) a two-way street. A voice is not unique unless someone hears it and recognizes it as yours. And this brings us back to the examples presented in this article and my main argument.

As we have seen, perfunctory, jigsaw puzzle and conjectural strategies were the main strategies used between the personnel and the participants when they communicated and tried to reach mutual understandings within the framework of the situations. But we also saw that these situations could fail in the sense that no joint meaning could be created within the framework of the situation because the able-speaking partner could not understand the impaired-speaking person's speech pattern. So, when relying on their voices, the participants will quite often not be understood. Thus (in many situations) no joint sense of meaning is created.

It is, however, not particularly strange that the communication strategies are based mostly on the act of speaking. As it has been concluded, the ideology of spoken language is strong in western culture and to not give up ones speech seems to be the

same as not give up ones own sense of self, ones personhood. To be able to speak is to (at least try to) be able to remain yourself. But then, there are *practical implications* that result from this ideology. In trying to keep ones personhood by not giving up speaking, it seems that what could happen is that one looses some of it anyway. Because, we are who we are in relation to others and if the communication then fails, our identities crumble.

Practical implications

By conducting a year long field work among people with severe communicative disorders I was able to detect three main strategies that were used in communication between able-speaking and impaired-speaking persons; perfunctory, jigsaw puzzle and conjectural. The three strategies that we have now seen are all based on the act of speaking. At the same time I have also tried to explain how we need to understand those strategies in relation to a wider context, where a western ideology of spoken language seems to be omnipresent which result in consequences in relation to meaning-making strategies such as identity- and personhood creation. I would like to argue that these consequences have practical implications on three levels: (1) for the people living with the communicative disorder; (2) for the health-care personnel working with these people; and (3) for researchers wanting to study people with communicative disorders.

First of all, the ideology of spoken language leads to practical implications for the people living with the communicative disorder in that it may result in not wanting to use facilitated or augmentative communication. And when they want to rely on the act of speaking they are very much dependent on that the communicative partner is familiar with their speech patterns and takes the time to really try to understand what they say. As Robillard (a professor of sociology, trained in ethno-methodological methods) has written when he himself got struck in mid-life by paralysis and loss of speech due to motor-neuron disease:

> Often those who communicate with me become impatient. [. . .] Some people complain that they cannot find their own sense of interactional competence in my elongated replies, and they break off further interaction after voicing their grievance. (1999, 64–5)

We have seen in the three strategies used, that the impaired-speaking person is very much dependent on that the able-speaking person knows him/her quite well and also that he/she is patient and lets the conversations take their time. In excerpt 2 we saw that it took Pete and I over 20 minutes to struggle forward to a joint sense of meaning using the jigsaw puzzle strategy. In a care-setting such as this, it is very rare that the personnel have such 20 minutes. . . . We also saw (in excerpt 3, the conjectural strategy) that same reaction that Robillard writes about, when Judith becomes impatient with Beth for screaming. Judith covers her ears and leaves the conversation, leaving the sense-making 'unfinished'.

As such, we see that the preference for speaking has very real-life implications for people living with communicative disorders; it often leads to 'broken' meaning-making (Hydén and Brockmeier 2008).

Secondly, we can also see practical implications for the personnel; at least if we aspire to the idea that people with disabilities should be in control of their own lives (Antelius 2009; Olney 2001). First of all, it means that the personnel need to be 'competent communication partners, who understand, respect, and support the

individual autonomy and competence of the person with disabilities' (Antelius 2009, 358). It thus also seems to mean that the personnel need to be the ones who are facilitating the conversations rather than using an augmentative communication aid (since the ideology of spoken language seems to mean that the persons with communicative disorders do not wish to use such appliances). However, it also means that they need to be very aware of the power-imbalance in these situations, because within an ideology of spoken language we find a hierarchy: those who are able-speaking are usually the ones in control over the situation. Just the fact that they are also able-bodied and can get up and walk away (as Judith did) while the person with disabilities mostly cannot, makes this an asymmetric relation and it is important to remember that (communicative) asymmetries do not vanish on their own (Karlsson and Hydén 2007; Linell 1990). If we want such asymmetries to not only be recognized but also changed, it becomes crucial for the personnel to be attentive to the communicative attempts of the impaired-speaking person.

Thirdly, this gives us reason to also focus on practical implications for researchers within this area. The ideology of spoken language seems to indicate an unwanted use of augmentative communication. The impaired-speaking persons of this study most vividly portrayed this. That however does not mean that their (oral) voices are *all* they use in order to try to create meaning within the situations; they also use their *bodies* to tell stories. By researching embodied/enacted ways of telling stories (as for instance Antelius 2007, 2009 and Mattingly 1994, 1998 have done) we could find alternative stories, stories that may contest the communicative asymmetry between able-speaking and impaired-speaking. And that, finally, would lead to one more practical implications for the personnel in health-care settings as this: to be a 'truly' competent communication partner to communicatively impaired persons means that one have to be attentive not just to their spoken stories but also to their embodied/enacted stories, stories they could tell by instance of how they occupy the space of a room (Antelius 2009).

Notes

1. In an article that argues for the importance of understanding interactive work and the joint construction of meaning it might seem paradoxical to transcribe excerpts in a linear way, leaving out overlaps, pauses, coordination etc. which are all important features of conversations and how a sense of meaning is created within such conversations. However, the linear way of transcribing the excerpts have been chosen on purpose as it intends to portray what often happened in these conversations, that one waited for the other to finish before trying to say something. I have instead tried to explain the excerpts more in detail in my analysis of them and in the commentary that follows the excerpts.
2. For the difference in meanings in facilitated and augmentative communication, I recommend Goode (1994, 197ff.). I have not put any stress on the different meanings in this manuscript as it is not vital to the general argumentation since both are 'rejected' by the participants.
3. I have chosen to use the term *spoken language* as it refers to Giddens (1991) and Ong's (1982) discussions about language and that articulated sound, especially the spoken word, is essential. I contemplated using either *verbalism* or *vocalism*, or even *oral speech*; however, it is not just 'sounds' that are preferred by the participants but rather 'actual' words and to be able to speak 'properly'. Hence, to vocalize something (or to be 'just' oral) is not 'enough'. And to use the term *verbalism* (as I first intended) was proven to be a bad idea since verbalism has a pejorative connotation to it, as it refers to excessive speaking.
4. Severe disability has various connotations; here it refers to both physical and communicative disabilities caused by brain damage in adult life that have had a profound impact on the participant's lives. Ways of communicating or interacting in so-called typical ways have

been altered and the participant no longer lives or works independently, being in constant need of around-the-clock personal assistance or living in sheltered housing (Antelius 2007, 37; Olney 2001, 87).

5. Kovarsky and Crago (1990–1, 48f.) describe the process of triangulation as that which is used within navigation; to try to locate your position by fixing more than one point in space. In ethnography the researcher, like the sailor in navigation, can triangulate his/her data in order to try to lessen the chance for errors because if the variety of data is triangulated the data can be validated through several resources. At the same time there is of course also the greater chance of finding interesting phenomena to study if one widens ones horizon.
6. By western culture I mean that part of the world that has descended from (Latin-speaking) Christian churches. In laymen terms that often means the American and European culture. It might be the case that this ideology of oral speech that I write about exists within other cultures, but as far as I have been able to tell (based on my own empirical setting in what would be called western culture and the literature that I have read that dwells upon the subject) it seems to be of greatest importance to western culture. For example, speech act theorists have been criticized by ethnographers of Pacific societies for placing centrality on intentionality which is thought to be rooted in western conceptions of the self and hence might not apply to local ways of producing meaning (Woolard 1998, 15; Woolard and Shieffelin 1994, 59–60).
7. Since this preference for speaking seems to be of most importance for people living in western cultures (which all descend from the Christian church) perhaps we could trace this preference all the way back to the Holy Bible? Perhaps we could even talk about the Christian creation myth, where God creates the world *by speaking*, as one of our grand narratives?

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Transcript key

.	a conclusive fall in tone
,	a continuing intonation
(.)	short pause
(*n*s)	longer pause, in seconds
?	rising infliction
italics	emphasis
* *	with laugher in voice
¤ ¤	low voice/whisper
underlined	raised voice
UNDERLINED	very high voice/screaming
. . .	repetition of what the other person has said
[. . .]	some data omitted
[ ]	context, not recorded audibly
[xxx]	inaudible