Podcast II: Aphasia from the perspective of nursing and speech therapy

"Understanding aphasia" from different perspectives. In our podcast series, we provide insight, clarify and create understanding for a disorder that changes language and life. My name is Ines Conzett, I am a speech therapist and I am delighted to be able to shed light on the topic of "Aphasia and interprofessionalism" in this podcast series. I am extremely pleased because these are precisely the two topics that are of interest to me in my everyday professional life.

Presentation

Today I have very interesting discussion partners, Jenny Weber and Stephan Behr. I'm very pleased to be shedding light on the topic today from a nursing and speech therapy perspective. Jenny Weber is a speech therapist, Stephan Behr comes from a nursing background and I would like you to introduce yourselves. Jenny, tell us where you come from and what you do.

J: I have been a speech therapist for several years now and have been lucky enough to see the whole spectrum of speech therapy work in connection with people with aphasia during this time. From the stroke unit, i.e. acute, acute post-stroke, to outpatients and long-term chronic sufferers, I've actually been able to work with almost everyone. And I couldn't say which is more exciting or challenging.

I: Thank you so much for being here today. And sitting opposite you is Stephan Behr. Nice to have you here, Stephan. I'd also like to introduce you briefly.

S: Thank you for inviting me to this podcast. I've been working in neurorehabilitation for 26 years now, including in various fields like Jenny, from the early phase and acute phase through to more advanced areas. As a result, I naturally have frequent contact with people with aphasia. I am currently employed as a care expert at Reha Basel. This means that I offer specialist advice, support for rehabilitative care and my focus is on movement support with the aim of improving independence in everyday life. I have completed various further training courses and am delighted to be here to provide information about the field of care.

Aphasia: from the perspective of speech therapy and care

I: Very nice, thank you very much. Aphasia, Jenny, what does that mean? What is aphasia?

J: Aphasia is a language disorder, i.e. when oral or written language is really affected after brain damage. There can be various reasons why the brain is damaged. And if you were previously able to read, write and speak normally and understand the language, that is no longer the case as it was before the event.

I: And how should we imagine this in the acute sector? What is the function of speech therapy?

J: We visit people within the first hour to days after someone comes to the ward and has a new brain injury. Then we first look at their language skills and try to take everything else into account, for example how they are feeling in general, etc. Then we make an initial small assessment. Then

we make an initial small clarification. This doesn't have to be an insane test, especially in the early days when so much else is still going on and is new. And above all, we also look at how we can support people communicatively so that they can communicate as much as possible when this might otherwise be difficult. Or also advising relatives, those affected and perhaps other settings as to what the most suitable strategies might be now if language is no longer working as it should.

I: Stephan, you have a lot of experience, including with phasic people. What is it like for nursing care when people can't express themselves?

S: Of course, a very, very important part of the strategies for building relationships with the people affected is missing. And that's a very, very important part of the rehabilitation process that we're involved in. What Jenny just mentioned, the beginning of rehabilitation, to find out what the needs are, what the habits of the people affected are. Of course, it's very important to know that it depends on the details, the little things and the history. In this case, we then fall back on the relatives. So that's something that we do very specifically at the beginning, that we collect information from the relatives about the needs, about the habits, to find out, because the language doesn't work, how we can react in certain situations, how we can organize the contact and so on.

Interprofessionalism

I: The topic of interprofessionalism is also something that is very, very important and is also of great importance to us in the podcast. How can we imagine this in rehabilitation? You will soon have experience of the rehabilitation process. This collaboration, it all takes time. How do you do that?

S: I would be the first to answer that, because the topic of time and care go very well together. There is always the issue of why. How do you do that? How do you organize it? For one thing, as carers, we are there 24 hours a day, seven days a week. We naturally have a very important role in rehabilitation. We see a lot, we are very close to the patients. We see them in different daytime and night-time situations, we see them at the weekend, we get to see family situations when relatives are there, including the interpersonal relationships between relatives and patients. So we have a lot of insight into the whole situation. As I've already said, we try to really observe the relationship-building process at the beginning, to see what actually works in terms of communication. What is understood and what statements are there that the person concerned can use in everyday life? And that takes time, that's for sure. You can't do it too quickly. And that's also something that we in the care sector notice again and again , where we have to set ourselves very strict limits in order to be able to ensure communication at all. To give them the time, to have the patience. And I think that's an important characteristic of rehabilitation. Without patience, it works very, very badly, or it becomes very, very difficult. You have to learn that and you also have to be able to endure the fact that there are phases or times when you may have to be even more patient in order to be able to clarify certain things and clarify circumstances

I: Time and patience are a very important aspect. And they are incredibly important on the way to getting well again or returning to function. In my clinical work, I have repeatedly experienced difficult communication situations. And then you had the feeling that the speech therapist was coming. And it's like, the speech therapist is here now. Jenny, what does the speech therapist do

differently? Or is it really the case that communication between the speech therapist and the patient is better? Or what makes it different?

J: Well, my experience has been that we don't necessarily do anything else. But when this time factor comes into play again, it's just that we usually have a more protected setting. The clinic is usually a special setting and provides a certain degree of protection. But if they don't come to us, they really do have half an hour, for example. And I've also taken that out for myself. Sometimes, if something was really urgent, I would simply take half an hour out to find out what was meant by it. And just being in the interaction for half an hour was very difficult for the carers because they were looking after so many people at the same time and there was so much going on on the side. We are usually in a quiet room if we are lucky enough have our own therapy rooms. We can try things out there and also have a lot more material at our disposal. We have visual material that we can pull out spontaneously. We always have the iPad in the logo room. The carers don't always have it to hand. You can also try even harder to find out what is meant in terms of understanding and comprehensibility.

I: So communication by all means, with the inclusion of pictures, writing, non-verbal possibilities, strategies. We are often asked in collaboration with working groups, can't you give us a picture book or a board? How does this work in everyday clinical practice? Are these good tools or is it difficult? What is really useful at the patient's bedside?

J: I think it very much depends on the situation. The most important thing, of course, is that the pictures are chosen in such a way that, ideally, the basic needs and the things on them can be shown. But of course it's not always what the person actually means and that's why it's very limiting. We often have 5, 6 or 7 standard things on it in rehab that are also relevant at the patient's bedside. There are things like thirst or the toilet, or music that is not always to hand. But it also depends on how the patient is able to deal with this. There are also books that have 600 pictures in them. But then, of course, you also need to know a bit about what's inside. And if it simply takes so long to find it, or if it's perhaps not even possible to do it motorically, then it's no use.

I: So the approach is also very individual, with different strategies and measures for each patient or each affected person.

J: Exactly, that certainly takes a lot of time to try out. It's also not the case that if it works today, it will still be the same method of choice tomorrow, which is why we test it regularly. And as a speech therapist, I always say that if it works in my speech room, it's no good if it doesn't work outside. Or vice versa, it may not work for me because it's not an issue, but completely different things are needed with the carers or relatives. That's why we often try things out and then go to the ward and talk to those affected and their relatives to see what they need above all. And they are also the ones who have to apply and practice it with the patients again and again.

S: I would like to take up the part about the protected setting again briefly. This is of course a huge advantage for us in care, that we can communicate about everyday activities. In other words, we don't have to come up with an extra therapy program, but we always communicate about what's going on. And there is simply a lot to do in everyday life for the people concerned. And that is of course a huge advantage. A therapist once told me that you don't have to think about anything in care, you can just do what you have to do. And of course that's something that, yes, that's true,

that's an advantage of our work. And that's where the aids are useful, but you can perhaps see in the situation what is wanted next or what the next thing is, and you can perhaps make a bit more progress with communication than in a protected, different setting.

Challenges in everyday working life and support / coping strategies

I: I imagine that when you are at the patient's bedside, communication is not always successful. How do you deal with such difficult challenges? Stephan, how do you experience it when communication doesn't work, when you don't have enough time? How do you deal with these difficult situations?

S: I would say that, firstly, we need to differentiate between whether there is any possibility at all of achieving the next step via yes-no communication or whether this is not possible at all. And of course we try to find that out first. And if that is not possible at all with a yes-no, then we really have to find out with a lot of patience, with empathy, and again with the time we have or don't have, what the issue could be now. And I think that by looking at the situation and the basic need that might exist, I realize that you can often reach a goal, perhaps a next sub-goal. If that doesn't work at all, it's good to get a second person to join you or another person in general, to go out, get another person and try to figure it out. And I believe that the habits you get to know over time often mean that misunderstandings don't arise in the first place. There's a process in which the person is involved, where you first have to get to know them and then realize, okay, maybe this is the issue or maybe it's not. And then you can perhaps come to an understanding through a process of elimination, do you want this - yes, no -, do you need this - yes, no -. And in the end, if you don't understand it at all, perhaps you can be honest and say, 'I'm afraid I don't understand you at the moment, I suggest I come back later' and then come back honestly and try again or take another person with you and try again.

I: Communicating openly and honestly is also a very important point. And addressing misunderstandings, not sweeping them under the carpet or pretending that I think I've already understood them, but communicating honestly, that seems to me to be a very important point.

S: I also think it's true that when you're confronted with a difficult situation over a longer period of time, even as a carer, as the person affected, of course, it's a burden. It really is something exhausting. And then you have to be honest and perhaps communicate this in the team. There is then the possibility in the care team that someone else might be assigned for the day or that you take turns. It's also important to find conversation strategies within the team to support each other. As well as, of course, involving the speech therapists in a quiet minute and describing the situation and perhaps picking up tips or asking other colleagues how it could work better next time.

I: It is also known that a lot of carers are leaving the profession. Are there ways to counteract this? As someone with so many years of experience, how did you deal with these difficult situations yourself?

S: Well, I think it crystallizes at a certain point when you work in neurorehabilitation. Is that my specialty or is it something I can no longer cope with in the long term? And it's best not to take a lot of things home with you, because the situations are of course very difficult to endure in some cases. As I said, you notice that after a certain time. And then, of course, if it goes in a negative

direction, you also have to make sure that you try to address it at work, discuss it with your supervisor, perhaps get help from experts, how can I compensate for it? And then there's the fact that we offer a wide range of psychosocial support in rehab. So I can get help in very stressful situations from the psychologists on site. I can also visit external agencies, contact them and get help there. And of course I have a team around me where I can talk about it and then address it. So there are various options. And I think you have to use that, you should use that, it should be known that it even exists, which it sometimes isn't. And it needs to be advertised. And it also needs advertising. And that's how you try to manage it.

I: What's it like in speech therapy? Jenny, these are difficult situations that you are confronted with every day. How do you deal with these difficult situations as a professional?

J: I think that if you're really in a situation and you're stuck, then I think it's important to communicate to the patient: 'I just can't get out of it yet'. And also to find out with them, should we continue to persistently try to find out? Or should we put it to one side and do something else? And when everything really escalates and tears are almost flowing, I've also left the room with people and simply decided, okay, let's not do anything that actually has anything to do with language or communication. And I have an example in my head - I didn't do it myself - but a colleague once had a flower pot smashed at that moment. Just to have some other outlet because it wasn't working linguistically or communicatively. I think you can also be very creative there. Especially in the rehab center in Basel or where I used to work, there was always a green oasis somewhere where you could go and perhaps clear your head. And I think that's also part of the interaction and communication. That we as therapists take the liberty of doing something completely different with people. That's how they are in the situation. And basically, it's also important to find a way, for me personally and for everyone who works in this field, not to take everything home with me. And then I think the team, both the speech therapy team and the interprofessional team, are very important in order to be able to exchange ideas and tell each other if something didn't go as it should have. Or to have the confidence to seek support. And what I always have to tell myself is that even the smallest progress, like one more word, can make so many differences, and to hold on to things like that. And also say that we usually don't know exactly what kind of patient it was before. And just take a look, okay, what was it like at the very beginning, what are our perspectives on this point and what have we achieved since then.

I: Turning the focus to the positive.

J: It's not always easy, but I think if you keep trying to tell yourself that, you can cushion certain frustrations.

S: That's a good keyword, looking on the bright side. I also believe that a humorous approach to everyday life can really help, as I've noticed in my experience. It doesn't mean that you have to make jokes all the time, rattle on or something, but that it's also good to have a laugh sometimes, maybe a comment about something. And then you realize relatively quickly whether the joke is getting through or not. And people are often so happy that they can just laugh or that they get a smile. And that's something I've noticed that you shouldn't forget, even in difficult or challenging situations, that humor and jokes can also help to achieve positive things.

I: I think we were able to gather together some very important things that can really help you in everyday life. And I would just like to add that I have always had good experiences with exercise. If we somehow reach our limits in the room, going outside, I always recommend that my patients go for a run in the woods, go outside, exercise, that can also make a difficult situation a little easier or open up the horizon. There is an educational video about interprofessional collaboration in healthcare. It's available on the YouTube channel . I think it's a very impressive recording of how complex the treatment of a person with an illness is. Nursing plays a very important role here.

Interprofessionalism: communication, institution and boundaries

I: What would you say, Stephan, are important factors for interprofessionalism to succeed?

S: Well, I think the most important factor, when we're already talking about communication with those affected, is that we communicate well with each other in the interprofessional team. Of course, this can be a corridor conversation, it can be a conversation where you perhaps listen. These are possibilities. But these are also very structured situations that should be used and can be exploited to the full. These are rehab coordination meetings, interprofessional team reports, so that you can keep exchanging information. Or the documentation that each profession does so that the other profession has an insight and can glean something from it. There are various factors that can help shape interprofessionality. Firstly, through communication and also by taking the other professional group seriously. And that's what you just mentioned, we have such an important part in rehabilitation, not only because we are there 24-7, but also because we have many opportunities to train things in everyday life or to transfer things from the therapies into everyday life. I'm thinking of the weekend, for example, when there are perhaps fewer therapies, then the nursing staff are there and can try out different things, do things that need to be consolidated and practiced. And, of course, there can also be an exchange with the speech therapists or physiotherapists, occupational therapists and the medical service. So I think I see us as a mediator somewhere, but also as a role with a major transfer function into everyday life.

I: So communication is a very important factor, but the institutions also have to provide the necessary channels for an exchange to take place, as well as an appreciation of the other professions. I think it's also valuable to have an overlap of knowledge, to know what area I cover and what my counterpart knows. So knowledge, which is also a very important factor, naturally also has to do with training and education

I: Jenny, where did you experience the limits of interprofessionalism? When do you say it just didn't work today? And what is the reason for that?

J: I think part of it is actually when you simply have completely different perspectives on it and a bit of a garden-variety way of thinking. That protects you to a certain extent, because you have your own perspective on it and you still have to keep a lot of other things in mind. But if you lack the work, the appreciation or the understanding of what others are doing. And that both are actually good and different perspectives. We also work very functionally at the beginning, in the first few weeks or months. I'm going to say classically, that would be the worksheets, as you might imagine, whereas in nursing it's very practical. And if we then work completely at cross purposes because we have the same person in mind, but simply set the focus differently because we can't understand it, then it is sometimes the same in the implementation - if we would like to train this here - if, for

example, we want to set fixed greeting phrases when everything is really difficult and we then try to get everyone to say it that way - and the others simply haven't seen it the umpteenth time when we have set it somewhere a bit like this. That these are simply things that really fail in terms of communication and other forms of cooperation, especially communication. That you just don't talk about the same things or not in the same way. And there's simply not enough time to read things in and pass on information.

S: I think that's partly due to the way work is organized. So if you now, here I say 'speech therapist' in quotation marks, you have your time, 30 minutes, 45 minutes, 60 minutes, whatever. And then that's a beginning and an end. And with us, it's completely different. We simply have different people that we have to look after and care for. And the way we organize our work is completely different. So you meet us in completely different situations than when we're not sitting there waiting for information, but we're always torn out of a situation or receive additional information. And I think that alone is interesting to take a look at.

What we once did, or what we keep thinking about, is whether it wouldn't be a good idea to swap roles, so that there is a time when the speech therapist, i.e. physio, works in nursing and vice versa. They could also run along and see how things work in the other areas. We try to implement this sporadically from time to time, but there is certainly still room for improvement for such a program.

I: The input we receive here is really, really great and valuable. I would like to motivate everyone who hears this to switch roles and to really raise awareness in the place where they are currently working. I believe that this is only possible if you take the time to change roles and gain experience. Now we've mainly talked about the acute sector, but also about rehabilitation.

Success in therapy

I: Jenny, you as an expert from the speech therapy side, a person with aphasia, how long do you do therapy? Is it even possible to say?

J: I can only say specifically about myself and the people I look after. It's very different there. Of course, it depends on how things progress. There are also people who leave rehab and we can say that I don't really need any more speech therapy. Maybe we'll give them some addresses in case there's anything else. And there really are people who I have looked after for years, almost. There it depends on what the people themselves want. How long do they have the goals they are working towards? I think that's always the most important thing, that people can tell me what they want to work on when they're back in everyday life. And if, of course, they say that it's right for them, or perhaps they're already a bit tired of therapy - sometimes that happens - I think you can take a break or see what else is needed, perhaps later, because then you can always start again with a new prescription for speech therapy. And then there is also the other option, that at some point the health insurance companies simply say that it is no longer profitable from their point of view. And then, of course, it depends on how we can then argue where we can still start, where we can still see progress, so that we then also get extensions. But now, how long that takes really varies a lot.

I: But you also said that it can sometimes be a year-long process.

J: Exactly.

I: You also look after chronic patients. What is your experience, Stephan? Do you sometimes see patients repeatedly where you think they've made progress again or have they regressed? How do you experience this in your everyday life?

S: So yes, I always see patients back at the clinic who are then in an outpatient setting. And if I know them from the inpatient setting, because I've been working in rehab for 20 years now, then I always try to make contact. And it's true that if the aphasia has of course existed for a very long time, then I now notice that major changes are rarely the case. But there are small changes, where a word is suddenly new. I noticed that again last week. I greeted a patient who I've known for a very, very long time. And suddenly he comes with me, I can't remember the word exactly, I think it was a new word when I greeted him, and suddenly it was completely new. And that surprised me so much because I'd never heard it before. And yes, of course I was pleased at the time. I think you were also pleased that this word was suddenly new. So these are little things, or supposedly little things, that you then recognize and hear again. And in this context, I could perhaps talk about our intensive aphasia program. This is something that we have now carried out twice on the basis that higher-frequency speech therapy or therapy at a stretch is effective. As I said, this has been carried out twice with a small group of patients in one department over a period of around six weeks. In other words, they are in a group for six to eight weeks in the same rooms and have intensive individual and group therapy, i.e. speech therapy and a self-training program. This is clarified in a preliminary discussion with the relatives. There should be an understanding of the tasks involved. Patients should be able to care for themselves to a large extent. And what we have seen after this two-time implementation with the respective small groups is that everyday communication has improved, even with long-standing aphasia. If you are interested, please contact the speech therapy department at Reha Basel. They will be able to provide more detailed information and perhaps people with aphasia and their relatives will also be interested in registering or getting involved.

I: Good luck with this exciting project. I think these are exactly the kind of offers we need in Switzerland. We have over 3000 affected people. You can read that on the Aphasiesuisse website. And I really think it's incredibly important for chronically affected people to continue to work in a targeted way and to be able to prove with research that it's actually making a difference. And above all, as you said, a new word sometimes seems to be something small and yet it can be incredibly valuable for the individual. What a great project.

Conclusion and future prospects

I: Jenny, in conclusion, what would you wish for in dealing with people with aphasia? A very open, very difficult question. Very briefly, what would you wish for people with aphasia?

J: I actually believe that you can make time for these people and that they dare to demand this time. On the one hand, because communication is simply so dependent on that, it works so much better. And secondly, simply to open up understanding or something like that. I've talked a lot about language and speech therapy, but that communication is so much more than just language. And that you can also benefit a lot from others in a group setting, for example, with chronic aphasics,

so that people know that they are not alone and can perhaps learn from others. Simply maintaining a little understanding of the whole thing and keeping an open mind.

I: I hope that with this podcast series we can have a slightly positive effect on understanding, that understanding for people who have aphasia is strengthened, that people are motivated to continue working on their linguistic and cognitive structures. And yes, I believe that speech therapists also make a very valuable contribution here.

I: Stephan Behr, you've been working in the healthcare sector for so long. You have a wide range of further training and specialist knowledge. What is your final statement? Aphasia and interprofessionalism: What else do you have and would you like to give us along the way?

S: Where do I start? So I think what is certainly important is that it would of course be great, especially in the care sector, if many people were interested in the field of neurorehabilitation, because it is still an area where we naturally also need staff, where it is often perhaps not so clear what the content is, what do I have to do? Is it perhaps too much for me? Is it too overwhelming? Is it too difficult? And of course I also hope that there are enough caregivers for people with aphasia who can support them in the very important phase of their illness, in their process. I believe that working in this area of medicine is a kind of advertisement for nursing. And the other thing, I think, or another point for me, would be to manage to perhaps not only think about aphasia in rehabilitation, because it is usually not isolated, but there are so many other issues at the forefront, and to try to promote them and increase the self-esteem of people with aphasia. In my many years of experience, I've noticed that if you manage to promote independence, even if it doesn't work so well with language, it still improves the quality of life. And I think that's an important part that you have to take with you, which I also wish for people with aphasia, that they have an offer where their general independence is promoted, because of course that also helps in everyday life and then also helps them in communication. Especially if they no longer have to rely on help so much, by promoting independence. In other words, to open their eyes to all the problems and difficulties they face, as well as to their families.

I: I realize I could talk to you for hours. I think it's such an important and exciting topic. We have really experienced people here who can provide information. Thank you very much for taking the time to do a bit of public relations work and share a bit of knowledge with the public. Thank you very much.

If you are still interested in aphasia and interprofessionalism, I would like to refer you to the other podcasts. Conversations with Prof. Dr. med. Susanne Wegener and affected persons with Urs Peter Michel and his wife Verena. Thank you very much for listening and, yes, good luck with your important clinical work

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