When the world becomes silent - signing clients' need of psychotherapy and challenges for the psychotherapist

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I am very honored to be invited to this very interesting symposia. So I would like to extend my thanks to Prof. Shiraishi Sensei and Prof. Shiomoyama Sensei, and I also want to say thank you to everyone in the committee of the Barrier Free Education. I am very happy to see my fellow speakers here, the educators, others in the audience. And last but not the least, the interpreters; without them, we could not have done this conference.

First I’d like to mention something about my research. My research has been focusing, to great deal, on parent-child interaction and particularly the parent and child interaction in the families of disabled: i.e. Deaf/hearing impaired children. I think that this interaction is the basic foundation for how we relate to other people and how we regard ourselves, how we relate to the future, also how we deal with difficulties that we encounter in life. This is the same for everyone, disabled or non-disabled, however the interactions in the family may vary and be affected differently by the disability.

From the beginning, I would like to state that I think anyone of us may become disabled. Furthermore, all of us may feel handicapped in certain situations. Without being disabled. I am certainly linguistically handicapped if I would not have interpreters in this symposia.

In Sweden, the fathers are very much involved in their children and Deaf children are no exception. The fathers participate sometimes in a way that we are amazed to see as professionals. As a consequence there is, in many cases, close interaction between fathers and their children in a short-term perspective and a secure basis in a long-term perspective. There are, of course, exceptions.

My doctor dissertation, presented in 1983, was (according to fellow-researchers in the U.S.) a pioneer work regarding the systematic work of parents of Deaf and hard of hearing children, the parents’ crises and how to deal professionally with the challenges the parents encountered in group counseling. One aim was to give psychological support to the parents in order for them to be able to support the children and influence the children’s future opportunities. The thesis was documented in English as monograph.

In my research, I had a lot of contacts with audiologists and with teachers for the Deaf and with parents. The first thing that actually got me into this research field was my interest for languages and how deafness influenced the individual cognitively, emotionally and socially. I did not have any personal experience I could relate to in these matters. I had to, excited as I am, make my own contacts with people who had the actual experience and with Deaf adults. My network in the field increased more and more throughout the years as did my awareness and the competence in the field.
I presented my dissertation at Stockholm University. Presently I am working at Karolinska Institutet. Karolinska Institutet is a medical university with many (more than twenty) different educational programs. The head of Karolinska Institutet, since 2004, is Professor Harriet Wallberg-Henriksson (we have a female head). At Karolinska Institutet we have a committee who suggests the annual Nobel Prizes. We also have a very famous photographer and honorary doctor, Lennart Nilsson, most well-known for the photos of the unborn child. Karolinska Institutet has a lot of international collaboration in research and in education. I have been a director of the psychotherapy program at Karolinska Institutet including the psychodynamic direction and the cognitive behavioral direction (CBT); i.e. the basic level and the advanced level. Presently I teach, supervise students’ clinical work, and I am the examination for the CBT education at different kinds of levels. And of course I do research.

My current research programs are actually two. I am working, with senior colleagues in a communication center at Karolinska Institutet, with hearing impaired in working life. Together with another group of senior researchers, I have started a project dealing with multiple sclerosis (MS) and CBT.

The title of my presentation is ‘When the world becomes silent. Signing clients’ need of psychotherapy and challenges for the psychotherapist’. My agenda has some undertitles: counseling/psychotherapy for the Deaf. Being Deaf, some important features which I think will fit in to what we have already been talking about regarding identity and the concept of disability. After that a case study follows with the permission of a Deaf woman who has been one of my patients. Then I will move on to talk about challenges psychotherapists working with Deaf clients have to deal with. There are quite a few, but there are also solutions to these. One question will be raised: who is the psychotherapists for the Deaf? Finally there will be some conclusions.

My presentation will be accompanied by photos I have taken myself and by music. Some of you may enjoy the music, others may enjoy the photos and some of you who can both see and hear may enjoy both means of accompanying features.

I think that it’s very difficult for us all to understand what it’s like and what really happens to a person who has lived a life like hearing and suddenly or in the process of years become interrupted in this life as a hearing person. As professionals we have to strive to attempt to understand. Hearing loss affects the relationships in the family, the relationship to the spouse, to the children, to the grandchildren. It affects the situation at the labor market, the work situation, the communication with colleagues and managers. It also affects what you enjoy doing in your leisure time. I think we cannot really imagine what it would be like if we were to wake up in the morning and didn’t hear the sounds we are surrounded by all day long. As hearing we can even decide not to hear, not to listen to something. Am I right here?
I also think that the first thing we associate with not hearing is music: i.e. that we cannot hear or listen to music. And like my closest Deaf colleague once asked me: ‘I never heard birds, what does it sound like?’ How easy is it to explain this to a fellow colleague? The only situation were we get close to understanding how it would be to live in a silent world is when we enter an artificial laboratory. And even then it is not possible to fully grasp the silent world since we have our language! Becoming Deaf in adult years may influence what kind of activities you are interested in and what kind of things you actually may do. With technical devices: i.e. hearing aid or sign language interpreters, you sometimes can do more than you think you can do, but many people also get stuck in thoughts about what they cannot do because of the hearing loss. ‘I cannot go swimming, I cannot listen to music, I cannot go to the theatre’. And many people find it difficult with the social interaction because they cannot interact with people like before. But difficulties are at the same time challenges that can be dealt with!

However, becoming Deaf and hearing impaired constitutes for many people a stress situation. It’s a situation that make you react in various kinds of ways and it’s a crisis for some people. Being a crisis means that some Deaf or hearing impaired need counseling, psychotherapy, or just need a very positive social network, because psychotherapy is not the only key to the challenges we encounter in life.

I will read out some citations here from people who lost their hearing and also later on became Deaf

‘Before I received hearing aids, I felt so unbelievable normal. It was a division between not having and having hearing aids. It was not a kick (: i.e. meaning that it was not a positive thing) and I became extremely depressive’

‘Being hearing impaired is like standing between two worlds: you hear too well to hear bad. But you hear to bad to hear well’

‘My whole life has been focused on music. For me, it is disastrous to become Deaf. I depend on my hearing and I cannot perform my profession’. And if you cannot perform the profession you love and you have, it is very, very difficult

‘I have experienced such shame and guilt. I lost my self-confidence, and I have had thoughts that no single man wants me. I advanced from a pop star to a disabled idiot’. I can tell you that this woman later on got a cochlear implanted and she became more able to enjoy the world she had previously been enjoying

‘It takes time to grasp and accept that one has hearing loss. You don't really understand what's happening’. There are many things, for example that many hearing impaired according to our studies are more tired than Deaf people and more tired than hearing people, which we think has something to do with the fact that they have to concentrate so much on what is being said.

Some professionals are more exposed to noise than others, for example, rock musicians. About 20%, according to a Swedish study, have a permanent hearing loss. But even if you are a musician in a symphony orchestra, it means that you are affected by noise to some degree. The exposure of noise
in a symphony orchestra may vary depending on where you are seated, hence the risk of getting hearing problems either increase or decrease.

In the world we have about 70 million people who are Deaf. In Sweden we have much less of course (about 10,000), but the biggest proportion of people who have hearing loss of some kind are the ones who are childhood Deaf. That means they are Deaf from birth or before they acquired sign language. And then we have a group of adult Deaf who have acquire their deafness or hearing loss later on in life. Finally a group of Deaf-Blind. These three groups have their own sign language interpreters who are certified in Sweden.

We know from research that there is a relationship between hearing loss and health. And we also regard hearing loss as a national health problem with considerable physical and psychological consequences. It’s more a rule than an exception of course when you get older, to get hearing problems. When you are about 60 years, approximately a fourth of us have a hearing loss. But today it’s also gradually more common that hearing problems creep down in age because many young people expose themselves to music directly in their ears.

When it comes to well-being, there is a little slight tendency that Deaf people report less wellbeing than hearing impaired people, and the tendency is even more when compared to hearing people. These results come from a self-reported scale which is validated and used in our investigations. We have also utilized another kind of validated scale demonstrating that actually hearing people are in much worse shape regarding well-being than hearing impaired people. So there are conflicting results.

Environmental view of disability

Sweden has an environmental view of disability, meaning that before the 70’s we regarded so-called disability as something a person has in his/her personal luggage, something which has to do with a personal trait. The disability organizations influenced our perspective to the concept disability becoming characterized by a more environmental view. For example: you can be handicapped in certain situations without being disabled. This view facilitates for us to recognize the barriers for the disabled. Furthermore, it has been possible to identify barriers in the environment, for example, the physical barriers in the work environment and the inaccessibility for different groups of disabled people.

Lars Kruth Ph.D. is the most famous Deaf person in Sweden. Lars Kruth became Deaf when he was 11 years old so he had acquired the language and is, by definition, an adult Deaf person. He was originally a carpenter, worked with the Swedish National Association for the Deaf and became an honorary doctor of Stockholm University in 1980. He has been struggling for the sign language in Sweden and he has also contributed to establish a school for the Deaf. Dr. Lars Kruth said that the
most difficult barriers to the society, when he was struggling for sign language, was that society did not listen to the Deaf people. The second most important barrier was that the society thought they knew everything regarding Deaf people. They lacked knowledge but they claimed they possessed knowledge. That's the two barriers he is emphasizing. I still have contact with him, he has been very important in my work, and he's 91 years this year. Another very important obstacle he has talked about is the attitudes of the society towards Deaf people. This may be the most pronounced obstacle still today to deal with for us. The UN proclaims that all humans are born free and equal in worth and human rights. Societies sometimes forget this.

Psychological support for Deaf people

In 1981, Sweden became the first country in the world to acknowledge Deaf people's sign language. And the fact that sign language got a linguistic status was very important and it also had implications for the education of hearing people. After 1981, you did not teach one sign for one word. You learned a whole language. So this was indeed very important.

As a consequence of the acknowledgement of sign language, sign language became regarded as Deaf children's first language. Moreover, Deaf people were regarded as bilingual and bi-culture. Deaf people regard themselves as a linguistic and cultural minority, not a disability group. That's very important to emphasize.

This is very essential. And this also emphasizes and support the Deaf group. Further, the stimulation came from the United States where there is a strong Deaf awareness and a strong Deaf culture. Many Swedish Deaf have Deaf Americans as role models. I think it's very important to have role models; it's also very important that there are Deaf people paving the way for other Deaf.

A positive self-concept for Deaf people is not based on how hearing they are; it’s based on how Deaf they are. Are you following me? No? it’s important for Deaf people not to compare themselves to hearing people and see how much less hearing they are. It’s much more important to kind of underline how Deaf one is and how much you sign and relate to the Deaf culture; i.e. looking at the resources and what you actually can do instead of focusing on the deficiencies.

Deaf people's social networks start early on in life; i.e. in the schools of the Deaf, and they are durable in the course of life. Many Deaf people have a very strong social network. And participating in the Deaf culture gives Deaf individuals a way of dealing with deafness and a sense of identity. I will tell mention later on that it’s not always possible to be included in the Deaf group, there are obstacles, but let’s start out here now with the possibilities the network gives.

Becoming Deaf implies gaining a new identity, but it’s not the only identity. It is one of several identities the Deaf person have. What I mean is, that in one situation maybe it's important to
emphasize that you are Deaf, in other situations it’s more important to emphasize what kind of profession you have.

If we move on to how Deaf people deal with problems which arise in life: where do they seek help do you think? Do they seek help from psychiatric services? From psychotherapy? Family therapy? Do they rather ignore their problems? Maybe suffering in silence?

Well, unfortunately I have to say that some Deaf people do ignore their problems and suffer in silence because they don’t think there is any available help and many are unused to seek help in the professional establishment. It has taken a long time before people in the Deaf culture sought for and began to receive psychological support. I noticed when I visited Japan recently, last fall, that you used to have a so-called therapy dog Chirori who was very appreciated in the work with disabled and elderly people.

There had been many different approaches to counseling and psychotherapy for Deaf people. I will very quickly go through those, so we can move on to the case study. There have been: group counseling, group psychotherapy, individual psychotherapy, psycho-drama and role-playing. Furthermore activation therapy, occupational. In addition, social group work, guidance programs, rehabilitation centers and psychiatric services for the Deaf.

Counseling and psychotherapy for Deaf has demonstrated that there has been a lack of resources; i.e. psychiatric services specifically designed for Deaf are scarce. But resources are still lacking. There has been an insufficient preparedness to receive Deaf people, and I think that this is still the case in our country, at least to some degree. There is also an insecurity of Deaf people's needs which may also have to do with the fact that they have not themselves looked for this kind of service. And still today there is a limited number of therapists for the Deaf. If I think about it: do I know of any psychotherapist who is Deaf in Sweden? The answer is no. So far. But I have a colleague who is studying on the basic level of psychotherapy and who will be ready in about 1 year.

We have psychiatric services specifically designed for Deaf people in Sweden, but there remains a big problem. The psychiatric staff don't always sign, making communication very difficult. It takes years to learn a language. The situation is very trying for Deaf patients which is understandable.

The main directions of psychotherapy are psychoanalysis, learning psychology, cognitive psychology. I cannot think about any nicer way than to hang up these three very important psychotherapy representatives in a cherry blossom tree in Miyajima. Here we have Sigmund Freud (psychoanalysis), 1856-1939 and B.F. Skinner (learning psychologist), 1904-1990 and Aaron T. Beck (born 1921) from Philadelphia who is cognitive behavior therapist (however Beck was originally a psychoanalyst).

So, if we’re asking ourselves: Can people who are Deaf apply for getting services in any of these psychotherapeutic directions? Deaf people often have limited choices. Most therapists for the Deaf
have, at least so far in Sweden, worked from a psychodynamic orientation. Deaf people have different needs just like hearing people have, hence the opportunities for psychotherapy are not accessible to a satisfactory degree for Deaf people.

But when Deaf people come to psychotherapy, they have much the same problems as hearing have except some things which I will tell you about later on. They come when they are in a crisis situation. When they encounter a changed life situation/role. When they have problems in their relationship; i.e. privately in their network at work. When they have difficult decisions to make. For example, one client came to me and asked. Do you think I should divorce or not? The choice is the choice of the client but as a therapist you can guide the client and help her/him to ask herself/himself important questions in order to gradually arrive at a solution.

Furthermore, Deaf people may look for support for psychological traumas, depression, anxiety, eating disorders, physical symptoms which actually may cover psychological problems. And then there is a risk for a member in the Deaf group of being excluded from the own social group. If we as hearing people get excluded, we usually have more than one social group to turn to. But because of sign language the Deaf person is more vulnerable for exclusion.

Cultural affiliation is very powerful, however also subtle, and sometimes it is very difficult to understand what Deaf culture may imply and what it is the Deaf client is demonstrating in therapy; i.e. what I should know and what I don’t necessarily have to know as a psychotherapist. Cultural influences is often unconscious for the person herself/himself so you cannot simply ask for this information. You can be alert but modest, interested but not curious, patient without missing out the situation in which you may have to confront, accepting but also alert to support the client to dare trying out new behaviors. Cultural affiliation may also influence from whom you choose to seek help. Hearing people usually have a variety of professionals to seek help from, Deaf people have limited choices.

The Deaf culture is transmitted in the schools of the Deaf. Culture stress is a reason for seeking counseling or psychotherapy, and that also goes for Deaf people.

I will now move on to a case study and I will present Karin (Karen in English) to you. Karin is a woman who was 26 years old when she entered psychotherapy. She was unmarried, having no children. By profession, Karin was teacher for the Deaf. Her history was that she had hearing parents and hearing siblings. Her family had refrained from learning sign language. Karin was integrated in a hearing school during her school years and that was a difficult part for her.

Karin learned sign language later on in life as an adult and she really wanted to get into the Deaf group. She had, however, to struggle to become integrated because she didn’t have the right sign language. There are right and wrong sign languages, and the right one is a Deaf’s genuine sign language. Since Karin hadn’t conquered sign language from early age she couldn’t master the ‘right’
sign language. So she was struggling.

When she came to individual therapy, she had a book with her. She was reading lots of books. And she asked me if I had read this particular book, which I hadn’t. However I bought the book and started quickly to read it. In my position, it was very important for me to understand Karin, her thoughts, how she related the material to herself and her own situation.

Prior to individual therapy, the whole family had been in therapy. I was signing to Karin but her family couldn’t sign to her. So I said, you communicate the way you usually do with Karin whereas I communicate with Karin in sign language. This was very painful for the parents to see that I was signing and they were not signing. And every time, every week for about one year, Karin’s mother cried at the doorstep every time she came for therapy. It was so painful for her to realize that she hadn’t learned to communicate with Karin.

The issues that Karin was working with was her family relationships which you might already have guessed. She was also working with dependency/independence, with a feeling of alienation with her Deaf identity but also with her female identity, with her professional identity, with her ambitions at work, with her self-esteem and self-confidence. She also had feelings of guilt and shame and Karin wanted to actualize herself. When she was in psychotherapy she said that, and I will now quote her: “When I think of myself I feel so very insecure deep down. I have thoughts and ideas but I don’t know how I am going to carry them out. So everything comes to nothing”.

Karin had been a very good student and had received good grades. She had been in the school of the Deaf later on. And she said that that strengthened her identity. And, once again, I quote her: “Up to the last minute I was insecure whether I should continue my education as a Deaf teacher or not. I decided I should do it, and now I feel I have chosen a very important work. I have a work that is meaningful and also fun. And so long as I get over this insecurity, I think I will manage it. But what I found most difficult with the work is that I must look to myself for the answers and I often lack guidance”. And this I want to share with you about Karin, that she didn’t have anyone to turn to and ask for guidance when she needed it. And also she came from a hearing family who didn’t learn her language, hence communication was not strengthened in her family.

When a client comes in therapy, she or he will bring in her or his personal luggage. It’s very important, and I relate now to Professor Keo, saying that we also have to look at the strengths and the resources. Very true, the clients own strengths is essential to assess in therapy.

Becoming deaf has an influence on the individual person, the family, the work situation, the opportunities in society. All of these colors the thoughts, the emotions, the physiological reactions and the behavior in a short-term perspective and in a long-term perspective.

In a cognitive therapy context you can administer and test yourself assessing how you look at
yourself-others-the future. The result may give you an idea where you are heading and what you might need help with.

Together with the client the psychotherapist describe the problems and gather information on behavior excess for example, conflicts with family (external) and tenseness (internal) and behavior shortage for example psychosocially isolation (external) and usability to relax (internal). Last but not the least the client’s resources are assessed, for example having succeeded to reach higher education (external) and struggling to get accepted in the deaf community (internal).

Some important issues when working with Cognitive behavior therapy; CBT are, for example:

- Creating a collaborative work situation with the client
- Making the therapy understandable
- Working problem-focused
- Challenging the client in the way he/she looks upon self-others-future
- Increasing the flexibility in the client's functioning and suggesting tools for constructive action; i.e. enhancing 'help to self-help'
- Giving home assignments
- Identifying recurrent themes, working with core beliefs, intermediate beliefs, automatic thoughts steering the behavior and having short-term/long-term consequences
- Identifying the client's resources when the client is presenting a core belief, for example 'I am worthless', the psychotherapist challenge the client with socratic questions: What kind of evidence do you have for this thought? What thought pitfalls interrupts you? How could you test the thought is true? Together in a collaborative empiristic relationship the client and psychotherapist analyze the results of these questions, what lessons there are to be learned and what conclusions could be drawn for the future. This becomes a model for how the client himself or herself can challenge destructive thinking.

Psychotherapy in the cognitive context is always followed-up in so-called booster-sessions in order to maintain the changes the client has reached in psychotherapy.

Cognitive therapy is a transparent form of psychotherapy there is no hidden agenda in therapy. It is very important to underline that the Deaf person must play the key role in situations that concern him or her since it is his or her own future and life situation that is at stake. Communication is vital for all of us whether in psychotherapy or in life as a whole. What is language? Harold Pinter, Nobel Prize Winner in literature in 2005, maintains that language is bridges that make us human. It is only when we have mastered words, have a language, that we have access to the mutuality of the human world and to the understanding that we give to and receive from each other.

Issues of psychotherapy
When we as psychotherapist work with deaf clients, what are the challenges? Well some of them are the following ones:

There is cultural stress in the Deaf community.
Deaf people have experiences of oppression to a lesser or higher degree.
In the Deaf community there exists a distrust to the mainstream society, meaning that there is not always a trust with the psychotherapists because other hearing people have made the Deaf person disappointed in many situations, not the least their families who are hearing in a majority of cases.
Communication is in a minority language when you use sign language.
There are conflicts about the language since many significant others do not sign. Sometimes the psychotherapist have to be the protection shield to that kind of feelings.
Most parents of Deaf have not been able to provide a language model for their Deaf child. One of the consequences of this is, as many Deaf clients express, an inability to deal with conflicts later on in life.
There has been a lack of effective language interaction during childhood.
The language barriers between Deaf children and their hearing parents has resulted in isolation from the hearing family.
It's a very essential challenge for the psychotherapist to attempt to understand the role that deafness plays in the identity of the Deaf.
There are difficulties trying to make an accurate assessment and diagnosis of the Deaf clients. Professionals sometimes make mistakes here due to lack of knowledge of deafness.
One challenge is to establish an alliance with the Deaf client.
Another challenge is to deal with communication breakdown since we are seldom sharing the same language.
There are difficulties for the Deaf client differentiating between emotional experiences and accurately describing and labeling affects.
In the Deaf community there is a more fluid definition of personal space challenging the psychotherapist.
Psychotherapy with Deaf clients by the means of sign language means having a sustained eye contact.
Psychotherapy with Deaf clients must be highly attuned to facial expressions and body language.

As you noticed there are quite a few challenges working with Deaf clients in psychotherapy. Now, how can we deal with these challenges? For a start, we have to try to put ourselves in the Deaf person’s shoes. Learning how to navigate in unknown territories where we don’t know the language nor the culture. Realizing it is indeed a cultural encounter in the therapy room: i.e. the Deaf vs. the psychotherapist. We have to deal with our attitudes and expectations as psychotherapist. Preferably we can also consult a supervisor. What can then deaf clients expect in therapy? “A Deaf client can only hope to be able to work with a culturally affirmative therapist” (Williams & Abeles, 2004).
Sometimes Deaf clients have to jump without parachutes so to speak. Meaning they may not have anyone who can keep them up in the air, nobody to catch them if they are falling. A bit of this we noticed from Karin’s story in the case study presented. And Deaf people furthermore have to act as their own “ambassadors”. Some deaf people are very fit to do this, other can do it fairly well while others are very hesitant to even try. When I think about the role of being an ambassador I can think of several international ambassadors but my thoughts go first of all to a Swedish former ambassador I admire; i.e. Jan Eliasson. Jan Eliasson with his warm, empathetic personality and ability to communicate to people having different languages, cultures, religions, knowledge levels, political orientation and so on can make people seen, heard, respected, understood. Furthermore instill hope and contribute to changes influencing people’s lives. Deaf people who have themselves been heard, seen, respected and understood have greater opportunities to act as so-called ambassadors for their own Deaf group.

One question which often arise when we talk about psychotherapy for the Deaf is: who should do psychotherapy for the Deaf? Who is most fitted?

- A deaf psychotherapist?
- A hearing psychotherapist who can master sign language satisfactory?
- A hearing psychotherapist with the help of sign language interpreters?
- Psychotherapy on internet?

Of course, there may not only be one answer to this question and even if one choice would be to prefer for one Deaf client, others may be open to two or more choices. Also the accessibility of psychotherapy is limited to Deaf clients so there may not be a choice at all. It is, however, important that the Deaf client and the psychotherapist can feel comfortable to communicate and a feel a genuine motivation to work together in collaboration where both parties are open to learn new things. And that there is a therapeutic relationship where mutual trust and understanding can develop.

In conclusion there are some points I would like to sum up in the following:

- It’s important to respect Deaf clients’ human rights and access to the opportunities in society.
- Furthermore taking responsibility of the consequences.
- It’s important with participation and collaboration with the Deaf at all levels of decision.
- It’s important offering a variety of therapeutic approaches to the Deaf community.
- It’s important enhancing Deaf people to acquire an education to become psychotherapists.
- It’s important with psychotherapists fluent in sign language sharing or, at least, are willing to try to understand the Deaf culture.
- It’s important with an increased access to sign language interpreters.

It’s important that the psychotherapist participate in a vital process within the frame of humanism,
fostering change and optimizing the opportunities for their Deaf clients. At last I'd like to quote Woolpert (1982): “To be humanistic is to be political. The humanistic perspective provides not only a new vision of the possible human, but also a new look at our political life. It points to the dangers and opportunities politics offers for actualizing our potentials as individuals, as groups, and as species” (p. 65). This is what I'd like to convey to all of you working for humanism. And with that I'd like to say in Japanese: "Domo arigato" (=Thank you very much)!